Tampere University

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”I CALL IT BIG BROTHER”

Patients’ experiences of a computer vision based examination of nocturnal epilepsy seizures

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ABSTRACT

Makkonen Jouko: ”I call it Big Brother” – Patients’ experiences of a computer vision based examination of nocturnal epilepsy seizures
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This study investigates patients’ experiences of a computer vision based home examination service of nocturnal epilepsy seizures. In the Nelli examination video, audio and depth-sensor data are recorded when a patient sleeps. An algorithm recognizes the seizures. The primary research question is to understand the user experience and other experiences of the patients and their caretakers in the use of the Nelli examination at home. As a part of this, user journeys, the role of information, and experienced behavioral effects of the examination service are investigated.

Seven participants were interviewed using semi-structured interviews, and one participant’s key-contact points with the service were observed. Qualitative analysis based on the grounded theory approach was applied to the data. Six themes were found: (1) Experiences of the use were mainly positive; (2) Privacy concerned and influenced the behavior of the participants. However, clinical purposes made that accepted; (3) Lack of information was a significant theme of negative experiences; Users’ expectations, prepossessions, or other experienced or mental input to the interaction, i.e., their (4) needs and (5) motivations influenced their experiences; (6) Patient experience has a holistic nature and is influenced by extra-use factors, e.g., patient’s history with the disease, the treatment of it and the healthcare process.

As a practical implication, design guidelines for the content of a patient tutorial were produced, covering aspects of (1) simplicity; (2) access to more information; (3) concerns about privacy and need for information about it; (4) the needs and motivations of users; (5) user questions about Nelli and its context due to the high importance of those in patients’ lives.

This research strengthens the previous findings that benefits for clinical treatment are significant motivators for overcoming downsides of self-monitoring for patients or their family members, patients need information about how they are being examined and experience the lack of it negatively, and that patient experience has a holistic nature which is not limited to the user experience of home-monitoring. For instance, the severity of the patient’s medical condition impacts the experienced downsides and motivations to overcome those and the information needs. However, how different conditions influence experiences is a matter of future research.

Keywords and terms: User experience, patient experience, medical technology, self-monitoring, computer vision, epilepsy.

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Abbreviations

GT grounded theory
HTI human-technology interaction
NEL Neuro Event Labs Oy
PRU Nelli personal recording unit
QDA qualitative data analysis
TAM Technology acceptance model
UX user experience
V-EEG video-electroencephalography

Contents

1. Introduction

This chapter briefly introduces the landscape of the patient-experience of medical self-monitoring technologies and its research in the field of human-technology interaction. From there, I move towards the aim and scope of this research: exploring patients' experiences of medical home-examination of epilepsy seizures. This chapter ends at presenting the research questions, study methods, and the structure of this thesis.

1.1. Patient experience of medical self-monitoring technologies

Patient experience has become an important factor in measuring and improving healthcare during the last four decades (Andersen et al., 2017; Golda et al., 2018; Kash & McKahan, 2017; Wolf et al., 2014). Moreover, prior research indicates that patients' experiences have an influence on clinical quality and patient engagement (Andersen et al., 2017; Wolf et al., 2014). Simultaneously, the use of technology in clinical medicine has continued its growth. Along with this development, self-monitoring technology used by patients in order to provide the information needed for their care has become more common.

Human-technology interaction (HTI, or more commonly known *human-computer interaction*, HCI. Further referred to as HTI.) researchers have widely adopted the territories of medical technology and patient experience as subjects of their research. Considering medical technology, especially when it is used by patients, user experience (UX) is part of patient experience, however, not a comprehensive part. UX of patients does not cover all broad aspects of patient experience because UX focuses on experiences of technology use. In addition, aspects of user experience models are less applicable in the context of patient experience (Andersen et al., 2017).

Patient experience or user experience of patients has been researched in the context of home-monitoring of various medical conditions, for example, cardiac conditions or diabetes (Andersen et al., 2017; Skov et al., 2015; Storni, 2014). This variance is important. In medical home-monitoring systems, especially in the case of severe medical conditions, patients experiences are impacted by, for instance, the responsibility of one's own treatment, burdens caused by the medical condition or the healthcare process, in addition to the use of the technology per se (Andersen et al., 2017).

However, the service aspect of medical technology-assisted home-monitoring, which is implemented as a service, has not been largely in the focus of user experience or patient-experience research. Notwithstanding, those have become more common in recent years, as have software-as-a-service systems in general. Understanding experiences of the overall service, not limited to the technology use, discovers a more comprehensive view of

patients' experiences in the case of systems implemented as a service. Furthermore, informing patients in this kind of medical services has been researched scarcely. Andersen et al. (2017) recognized the need. In their study, patients felt being uninformed, uncertain, and had various expectations related to their self-monitoring system. Information reduced uncertainty. The results of Andersen's study show the need for informing patients about self-monitoring systems and for careful investigation on what needs do patients have regarding the information. Skov et al. (2015) researched patients' experiences related to information in the context of cardiology.

In particular, home-monitoring of epilepsy has been scarcely investigated. As said before, patient experience is heavily influenced by the disease or medical condition in question. Therefore, it is important to investigate patients' experiences in the contexts of different medical conditions. The impact of the HTI-research to clinical practice has been limited (Blandford, 2019), and the need for more research, especially from subjects close to clinical practice, is relevant.

1.2. The aim and scope of this thesis: the patient experience of the Nelli examination

This empirical study focuses on exploring patients' experiences of medical home-monitoring service and the role of information in the patients' experiences. More specifically, the service under inspection is the so-called Nelli examination, which is a home-monitoring service of nocturnal (i.e., night-time, or in some cases, mid-sleep during day-time) epilepsy seizures. Epilepsy is a chronic disease of the brain characterized by a tendency to recurrent seizures, which are brief episodes of involuntary movement and decreased level of consciousness of varied magnitude (Atula, 2019; *Epilepsy*, 2019).

Nelli is used for examining the quality and number of patient's seizures in order to provide the information needed for treatment for the clinicians. Based on self-reporting, the seizure documentation of nocturnal seizures is shown to be inaccurate (Peciola et al., 2018); therefore, monitoring provides more reliable results. Nelli is typically used in a patient's home for an examination period of four weeks. Nelli records video and audio of the patient every night, out of which computer-vision and algorithm recognize seizures. Nelli is a product and a service of a company, Neuro Event Labs Oy (NEL).

This research investigates patients' experiences on a wider horizon than only technology use. Therefore, it is more descriptive to use the term patient experience as a subject of this research, rather than user experience. Besides increasing knowledge of the patient experience in general, this research aims at helping NEL to understand their patients better in order to improve their product and service. Before this master's thesis, the patient experience of the Nelli examination had been scarcely investigated and therefore needed more research. Considering user experience, the medical staff is the primary user group of the Nelli examination because they prescribe the examination and eventually read and

examine the results. However, NEL considers the patients as one of the primary stakeholder groups and at least as important as the medical staff. Therefore, understanding the experiences of patients is valued. Furthermore, a remarkable share of the examined patients does not use the device themselves, but rather their caretakers do. Therefore, also the caretakers' experiences are included in the scope of the research, hence further in this research, the group of patients and their caretakers are referred to as *users*. Caretakers include, for example, family members or nurses. The expectations and experiences of different types of users are taken under investigation in this research.

The findings of this research were used to inform the design of content for a patient tutorial of the Nelli examination, which was done as a practical part of this research. This thesis was done partly commissioned by NEL. I conducted the user research and design of a patient-tutorial content as a paid intern.

The research is qualitative by nature. In the context of this research, it means understanding and explaining patients' or their caretakers' experiences of using Nelli or undergoing the examination process. For instance, what do they think, or how and why they act in each part of the process? What is problematic or experienced positively, and why? Subjective perceptions of emotions are investigated, as well as needs and motivations. Special attention is given to the role of informing and instructing users and how they experience that.

1.3. Research questions, study methods, and structure of this thesis

The primary research question is: **(1) What kind of user experience and other experiences of the patients and their caretakers arise in the use of the Nelli examination at home?** Nelli examination is a medical examination that is implemented as a service and which includes technology in the form of software as well as physical devices. The user experience research investigates all of these aspects, including the overall experience of the examination, the use of the device, and experiences on the service process before, during, and after the examination period. The nature of the Nelli examination raises topics worth investigating as a part of this question. How do patients experience being monitored during their sleep and in their homes, especially considering privacy matters? Are there other privacy matters experienced? What kind of influence it has on the experience when the video is analyzed by a computer versus a human? Does the context of clinical medicine affect the experience somehow? Studying these distinguishing, descriptive, and potentially intrusive factors of the examined service can give interesting and useful findings, both for the development of the product and in generalizing the findings for other medical home-monitoring systems. These questions are intentionally subordinate to the primary question and the user-research findings. Following the bottom-up approach, the user-research findings were allowed to guide the direction of the research, and other themes than

the ones set beforehand were investigated further if they emerged during the user-research.

The primary research question has three parts or sub-questions, which clarify and direct the areas of particular focus. In order to understand the experiences of the Nelli examination as a service, one sub-question is, **(A) what does the user journey of patients or their caretakers consist of?** This is investigated in order to understand how the service process is experienced from the users' perspective. This question includes seeking positive or negative experiences, events, or problems in patients' journeys in order to use that information in the patient-tutorial-content design. I use user-journey maps for visualizing the user journey of the users along with the service process, in order to understand the service process from patients' and their caretakers' perspective and to point out when certain experiences occur and how they are related to the service process. Potential questions, difficulties, annoyances, or positive experiences of the users and how are those placed in the service process are studied and visualized in the journey map.

The second part is, **(B) what is the role of information in patients' experiences?** What users need or want to know before, while, and after the examination, how these needs are answered, and how users experience the answers? This is closely related to the sub-question (A) because the temporal locations of these events, for instance, the points of needing, receiving, or lacking some information related to the service process, are investigated.

As the third part, the question **(C) how do the patients or their caretakers experience the behavioral effects that the examination possibly causes**, is examined. Potential influence in the patient's behavior is one focus point in the user-research in order to understand the level of interference the examination causes in users' everyday life.

These research questions are studied in order to achieve a sufficient overview and understanding of the patients' and their caretakers' experiences of the use of the Nelli examination and the service related to it. The context of the research and the Nelli examination is presented more thoroughly in Chapter 2. Previous literature on the subjects of this research is presented in Chapter 3.

An inductive, "bottom-up" research-approach was suitable for the twofold goals (i.e., scientific and product development goals) of this research. In practice, in the data-gathering, it meant a multi-method approach with the focus on semi-structured interviews. Seven participants, including patients and their caretakers, were interviewed, and in the case of one participant, key contact points were observed. In addition, other materials, for instance, pictures or e-mail discussions, were collected. The analysis-approach was based on the grounded theory approach, however, in a wide and flexible sense of the term. The user-research data were analyzed by qualitative analysis and open coding. The research and analysis methods are explained in Chapter 4.

Chapter 5 presents the findings and themes that emerged in the user-research and describes the user journey and service process of the Nelli examination from the patient perspective. As a practical implication of the results, a patient-tutorial content of the Nelli examination was designed, which will be presented in Chapter 6, including reasoning, how the findings informed the design, design guidelines, and a proposition of the content. Finally, Chapter 7 presents discussion and conclusions.

2. The context: Nocturnal epilepsy seizure examination with Nelli

Understanding the context of the research requires knowledge about Nelli and the service process related to it, as well as epilepsy and the treatment of it.

Epilepsy is a chronic disease, more exact, a set of diseases, of the brain (Tarnanen et al., 2020). It is characterized by a tendency to recurrent seizures, which are brief episodes of involuntary movement and decreased level of consciousness of varied magnitude (Atula, 2019; *Epilepsy*, 2019). It is treated with medication, which aims at controlling and reducing the seizures. Surgery might be a beneficial option for patients with severe epilepsy or who respond poorly to drug treatments. In addition, as an alternative treatment in cases that are severe are difficult to treat, are electrical stimulations to the brain or nerves (Atula, 2019; *Epilepsy*, 2019). For instance, some patients referred to in this study had had deep brain stimulation or vagal nerve stimulation treatments.

Planning the treatment or examining the treatment response requires information on the seizures and other symptoms. It is a recognized issue that based on self-reporting, the seizure documentation of nocturnal seizures is inaccurate, and the number and the frequency of them are often under-reported (Peciola et al., 2018). There is a need for accuracy in seizure documentation, which is one reason for using the Nelli examination for clinical purposes.

Nelli examination is a product and service for examining the amount, frequency, and quality of nocturnal (i.e., mid-sleep) epilepsy seizures and other epileptic activities. It is prescribed for the patient by a clinician, typically a neurologist. This is often done before or after some specific treatment, in order to see the starting point or evaluate the effects of the treatment.

This study focuses on the home-use of the service. Therefore, the actual context-of-use is a patient's home or other normal living environments, for instance, a nursing home. The caretakers of patients are included in the research due to the remarkable number of examined patients who are not themselves using the device because of, e.g., disabilities or their young age. That being the case, the *user* is rather the caretaker. In this study, participants included both patients and caretakers. Therefore, in this research, the group of patients and their caretakers are referred to as *users*.

The examination takes place in a patient's home, usually for a period of four weeks. A personal recording unit (PRU, see Figure 1) is installed next to a patient's bed. It is a set of devices, integrated together, with a built-in camera (The Intel® RealSense™ D435) and a computer (Intel NUC, for instance, model Intel® NUC Kit NUC7i3BNK), mounted to stands (K&M 26735 Speaker stand and Joby Action Clamp & GorillaPod Arm) and a remote control. PRU transfers data wirelessly. A power cord is needed. Total height can vary from 1.1 m to 2 m, depending on how and where it is installed. However, typically there is no need to extend it to its highest.

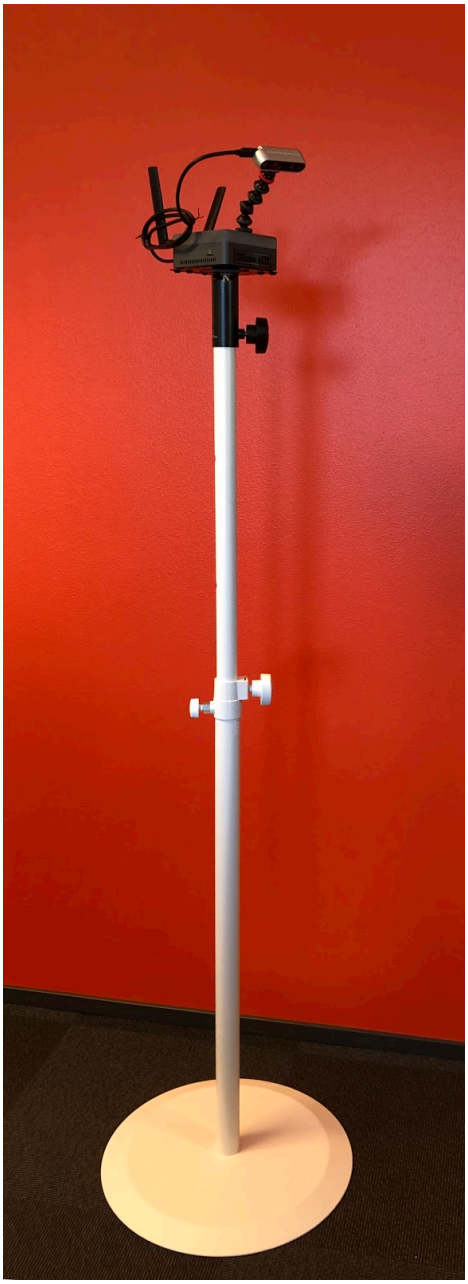


Figure 1: Nelli PRU mounted on a stand. (Published with permission of NEL)

The PRU records video and audio of the patient's bed. The patient's or caretaker's task is to switch the recording on when going to sleep and off when getting up from the bed. This is done with the remote control (Figure 2), which, together with a multicolor LED-light indicator, is the user interface for home-users.

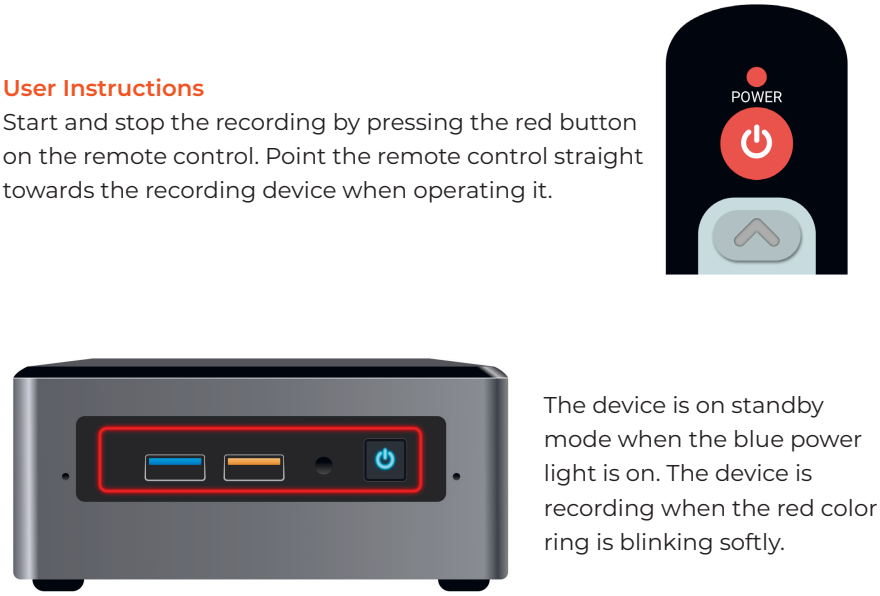


Figure 2: The user interface of home-users of Nelli, as presented in user instructions. It consists of remote control and LED-light. (Published with permission of NEL)

Nelli examination utilizes a convolutional pose machine (CPM) (Ramakrishna et al., 2016) to automatically recognize the epileptic seizures from the patterns of patient's spatial movements in addition to audio patterns, which both are recorded by the device. The software system automatically recognizes epileptic activities and seizures, and medical experts at NEL sort and verify the findings from the video. This analysis is started during and finished after the examination period. When the analysis is done, usually within two weeks after the end of the examination period, a report is sent to the doctor who prescribed the examination.

As a point of reference, video-electroencephalography (V-EEG) is used to some extent for similar examination purposes than the Nelli examination. According to Mervaala et al. (2012), it is an integral method for differential diagnosis of seizures and one of the most important examinations for diagnosing epilepsy. Electroencephalography (EEG) measures the electrical activity of the brain. Typically, in order to measure EEG, electrodes are placed along the scalp. In V-EEG, video and EEG are registered simultaneously (Mervaala et al., 2012).

In comparison to the Nelli examination, for examining epilepsy seizures, V-EEG gives more and different types of data. Recording EEG is important for examining seizures because epilepsy seizures are specifically caused by electrical disorders in a group of brain cells (*Epilepsy*, 2019; Mervaala et al., 2012). However, the typical duration of the V-EEG examination is 4–5 days (Fitzsimons et al., 2000; Mervaala et al., 2012),

whereas the examination period of Nelli is usually four weeks. This is one of the differentiating factors in the use of these two examination methods. Although not collecting as comprehensive data, for certain purposes, a benefit of Nelli is the longer examination duration because due that it can capture more seizures. In addition, it is done in a more normal environment of the patient in the patient's home. V-EEG can be done in well-equipped hospitals: in the case of Finland, central hospitals are equipped for shorter V-EEG examinations and actual V-EEG units for conducting examinations of multiple days locate in university hospitals (Mervaala et al., 2012). In addition, V-EEG examinations are relatively expensive, and they require healthcare personnel continuously for multiple days. However, supervision conducted by nurses is part of the examination and adds beneficial information. As a whole, V-EEG is beneficial for all patients for whom it has been prescribed to (Mervaala et al., 2012). Nelli examination is not an equivalent alternative examination for V-EEG, rather complementary, or sometimes they are located in different parts of the patient's treatment path, and they answer in different needs. As a more cost and resource-effective alternative, it can be more easily prescribed and conducted.

The comparison to V-EEG is relevant, considering the context of this research because some of the participants had had V-EEG examinations or were possibly about to have one. Some of them compared these two examinations spontaneously. It is also one example of possible other events in the patient's treatment history or plan, which are an essential part of the clinical context of the Nelli examination and further, this research.

Because Nelli is meant for an examination of a medical condition, the reference for using it comes from a clinician, by medical reasons: when and why it is used is decided by the doctor. Therefore, the context of healthcare and clinical medicine is an essential part of this study. On the other hand, due to the concept of home-monitoring, the use-context is in the patient's home. This offers an interesting area of investigation when these two contexts intersect.

3. Background and previous work

This chapter presents previous research and literature on topics of this study, including topics of research questions as well as topics that emerged in user-research. It starts by presenting how patients' experiences have been previously studied in the field of human-technology interaction, presents the terms of patient and user experience, and defines how those are used in this study. After that, the most relevant prior studies and literature on experiences of medical self-monitoring are presented. Themes and findings from previous literature, which are related to the research questions of this study, are presented. These consider the bond of patient experience of home-monitoring and extra-use factors and the role of information in patient experience.

3.1. Studying patients' experiences in human-technology interaction: patient experience and user experience

Patient experience has been researched in multiple fields, for example, medical science, nursing science, and human-technology interaction, which might be a reason that the definition of patient experience varies (Andersen et al., 2017; Golda et al., 2018; Nelson et al., 2018; Wolf et al., 2014; Zraick et al., 2016). In a systemic review, Wolf. et al. (2014) sought definitions for patient experience, and findings were mostly related to the quality of care. The following definitions are relevant considering this research. First, *Continuum of care* refers to that patient experience "spans over time and includes many touchpoints," it is broader than the care itself and refers to the "quality and value of all interactions." Second, some of the definitions Wolf et al. (2014) found focused on patients' expectations and evaluated patients' experiences after treatment if the expectations were met. Third, patient experience does not limit to measuring patient satisfaction. Finally, as a humoristic, nevertheless ingenious, conclusion, Wolf et al. present a description from The Free Dictionary: "How the patient feels/felt, i.e., good or bad, as/after he or she undergoes/went an episode of care." It underlines the lack of and need for definition, nevertheless summarizing the concept adequately.

A common concept of studying experiences in human-technology interaction (HTI, or more commonly known human-computer interaction, HCI) is user experience (UX). In ISO standard (International Organization for Standardization, 2019), user experience is defined as:

> user's perceptions and responses that result from the use and/or anticipated use of a system, product or service

This is commonly related to technology use. Hassenzahl and Tractinsky define user experience as following (Hassenzahl & Tractinsky, 2006, Figure 3):

> UX is a consequence of a user's internal state (predispositions, expectations, needs, motivation, mood, etc.), the characteristics of the designed system (e.g.

complexity, purpose, usability, functionality, etc.) and the context (or the environment) within which the interaction occurs (e.g. organisational/social setting, meaningfulness of the activity, voluntariness of use, etc.)

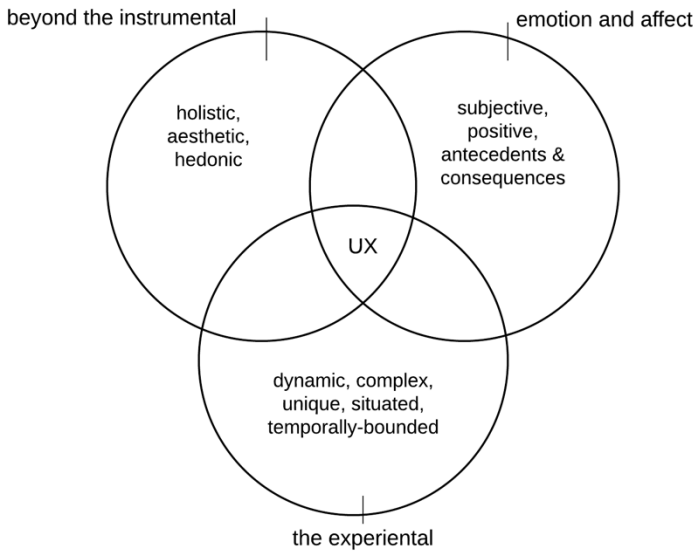


Figure 3: Multiple aspects of users' interactions with technology form user experience holistically. (Hassenzahl & Tractinsky, 2006)

Concepts of goals and needs are relevant in HTI and user experience. Goals drive the actions of users, as people in general. Goals have different levels, starting from background motives for doing something, goals for doing some concrete thing, and motor goals related to how the concrete thing is executed (Hassenzahl, 2010, p. 44). Hassenzahl argues that psychological needs work as the basis of categorizing positive experiences.

Compared to the Technology acceptance model (TAM, e.g., Davis, 1993), user experience models cover the emotional and experienced aspects broader (van Schaik & Ling, 2010). In the context of this research, TAM lacks coverage of experiences.

However, all methods, measurements, and frameworks of UX do not apply as well to the context of healthcare or clinical medicine (Andersen et al., 2017). The emotional dimensions of UX, i.e., aesthetics, hedonic dimensions, or eudaemonic aspects (Hassenzahl & Tractinsky, 2006; Mekler & Hornbæk, 2016), have been found to be problematic or less applicable in the context of healthcare and medical technology (Andersen et al., 2017). In addition, user experience and patient experience have different perspectives on people, who are the ones experiencing, namely, UX investigates users' and patient experience patients' experiences. Therefore, equating patient experience with the user experience of patients is not well-grounded.

The definition of user experience by ISO is used in this study, however acknowledging that in the context of medical self-monitoring technology, the experiences of patients are influenced by broader aspects and do not limit to direct responses of technology use.

Therefore, this research does not limit to studying user experience. A more suitable term to describe the overall subject of this research is patient experience because it covers broader aspects (see Figure 4). On the other hand, the loose definition of the term is acknowledged. Here I use it in the meaning of *patient's experiences, before, when, and after the patient undergoes/went an episode of care*. Summarized and taking these definitions into consideration, in this study, I investigate patient experience, focusing on, but not limited to, user experience, in the context of Nelli examination.

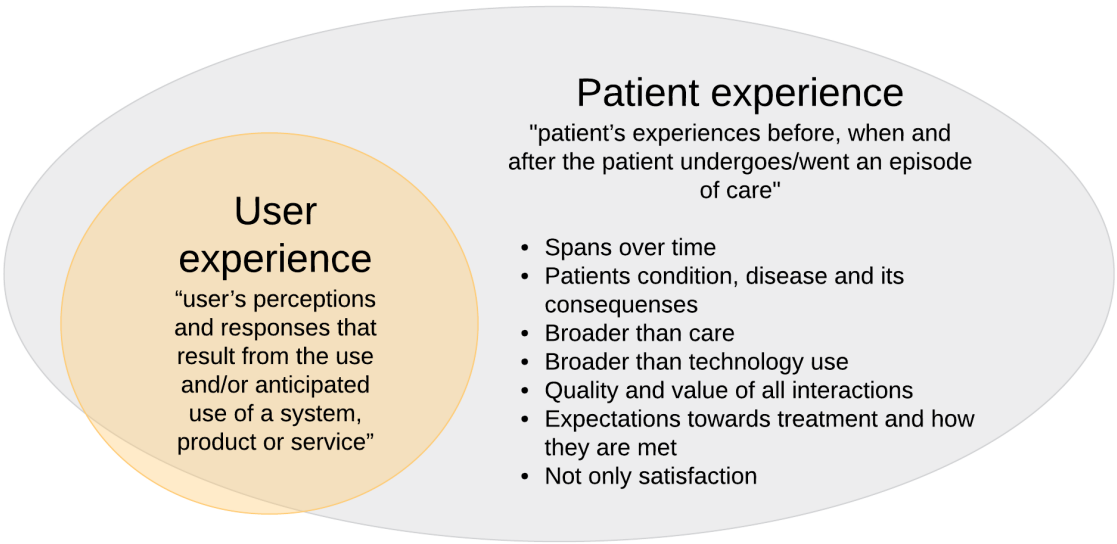


Figure 4: Patient experience covers more than user experience.

Andersen et al. (2017) offer guidelines for researching patient experience in the field of HTI and proposes three dimensions for user experience (UX) research and design in patient-centered e-health: *connectedness*, *comprehension*, and *compassion*. They studied patient experience through a deployment study in remote cardiac monitoring.

Based on their research, patients' emotions are grounded on negative feelings. Positive experiences "emerge from receiving feedback on symptoms and from continuous comforting communication with clinicians" (Andersen et al., 2017). Often patients' experiences are relational and interpersonal: like the patients themselves, so are their experiences, often connected to other people (e.g., relatives, friends, formal or informal caretakers). Probably as the most important finding related to the current study, according to Andersen et al. (2017), patient narratives about their experiences are "individual, unique, and situated," which means that they are based on arbitrary memory of the patients. However, it is noticeable that the last finding of Andersen et al. (2017) is, to some degree, related to the phenomenological analysis approach and creating patient narratives.

They proposed connectedness as UX-dimension as an answer to patients' need for feedback and supported by that feedback reduces negative experiences, even if it would be an automatic message (Andersen et al., 2017). Comprehension is suggested because

patients' negative experiences are related to their competence to comply with their condition (Andersen et al., 2017), and knowledge is a critical part of this competence (Storni, 2015). Therefore designers should orient towards "towards making it easy for patients to develop self-care expertise" (Andersen et al., 2017). Compassion answers to patients' individual needs for sympathy and empathy (Andersen et al., 2017).

3.2. Prior literature on experiences of medical self-monitoring

3.2.1. The most relevant prior studies on experiences of medical self-monitoring

This subsection presents the most relevant studies of the most similar context and subject, considering the current study. Grönvall & Verdezoto (2013) studied non-functional aspects of home-based healthcare technology and found seven themes: *people*, *resources*, *places*, *routines*, *knowledge*, *control,* and *motivation*. By *people,* they mean the individuality in the experiences of home-monitoring (e.g., patients' have a difference in the severity of their disease, which causes them to experience the monitoring different), and other people related to the life or the care of the patient. *Resources* refer to the resources of personal health management, including the self-monitoring devices as well as other recourses like a laptop or a notebook. *Place* refers to the spatial dimension of monitoring, as in benefits and problems of different places of monitoring, freedom considering mobile devices, as well as places that are related to the *routines* of monitoring. They found an "aspect of learning about oneself and one's condition directly connected to the act of self-monitoring" and further leveraging this *knowledge* in their daily health-management. This is related to the perceived increase of *control* for the monitored person. Different directions of the shift of control were found, considering patients, people close to patients, healthcare professionals, and the system behind monitoring. Finally, *motivation* related to health (to maintain the health of own or a family member or to get well or achieve a better state of health) appeared relevant, however highly individual and complex by nature.

Grönvall & Verdezoto (2013) found interesting differences between medical self-monitoring devices (e.g., blood pressure and blood glucose monitors) and wellness devices (e.g., pedometers or bodyweight scales). Some patients call medical devices "illness devices." They were kept hidden from other people, unlike wellness devices.

Andersen et al. (2017) found six key themes in the patients' experiences in remote cardiac monitoring:

> Coping with unexplained symptoms, being uninformed, feeling uncertain and anxious, dealing with identity change, concerns about new responsibilities, and having expectations.

They argue that "patient's emotions are grounded in negative feelings," and positive experiences "emerge from receiving feedback on symptoms and from continuous comforting communication with clinicians" (Andersen et al., 2017). *Coping with unexplained symptoms* can refer to various things in their research context of an insertable cardiac monitor (ICM). Patients need to cope with the symptoms which are experienced by the patient and detected by the ICM, the symptoms which are experienced by the patient and not detected by the ICM, or the symptoms which are detected only by the device. Different situations caused different emotions and experiences (Andersen et al., 2017):

> Consistency between symptoms and signs often helps the patients cope with their condition, whereas inconsistency between symptoms and detected signs can create frustration and discouragement.

Andersen et al. (2017) discovered that patients have a need for information related to the situation in which they are waiting for their diagnosis, as well as the process of their home monitoring, in which they are not contacted by their clinician unless it is necessary. *Being uninformed* refers to the negative experience of this need is not met. Patients were *feeling uncertain and anxious* when they were waiting for results, or in some cases, other events in their treatment process. Information reduced this uncertainty. Some patients were *dealing with identity change* due to the disease or changes in it, which patients experienced influencing their behavior or social interaction. Another change was the increasing responsibilities of their own treatment, which caused *concerns about new responsibilities* and difficulties of living up to them. Finally, home monitoring created new *expectations* from and towards patients and clinicians, related to, for instance, a patient being understood or having feedback or clinician showing sympathy, or a patient using the device correctly.

Storni (2014) mapped issues and concerns related to chronic self-care of diabetes. First, he stated that the chronic nature of the disease causes compromising and balancing for patients between the medical aspect of the disease and daily life. Second, there is wide variability in the severity of the disease as well as in attitudes towards it and practices of self-care. Third, he mentions that the relationship between patients and medical experts is often problematic, especially when it is characterized by relevant asymmetry (Storni, 2014).

Skov et al. (2015) focused on patients' experiences related to information when using an implantable cardioverter-defibrillator (ICD). Their findings differed from previously mentioned studies. It is remarkable that patients with ICD are typically at the risk of sudden death. Their participants were satisfied with the monitoring without being informed about the collected data or monitor functioning. Most of the participants did not mind being closely monitored, which was referred to be in line with previous research: people with severe health conditions were likely to share their private data (Vines et al., 2013).

The participants did, however, feel anxiety for several reasons, including the monitoring. It, for instance, reminded them about their illness. Skov et al. discovered *a safety paradox* created by ICD remote monitoring:

> a safety paradox of patients *feeling less safe* while actually *being safer* because some of them became more anxious while living with their monitor

3.2.2. Patient experience of home-monitoring is bound to extra-use factors

Self-monitoring or other applications of medical technology do not function in solitude. The use of them is influenced by, for instance, other people, resources, or places (Grönvall & Verdezoto, 2013). The patient experience overall is bound to a context: it is relational, individual, and situational (Andersen et al., 2017; Grönvall & Verdezoto, 2013). This subsection presents previous literature on these contextual extra-use factors.

It is noticed in several studies that patient experience is influenced by the patient's disease or condition, which a patient is having or suspected to have. The condition or disease determines, for instance, the potential consequences of them, which impacts the experience. For example, in studies about patient experience of cardiological monitoring, the risk of life-threatening condition with heart caused anxiety (Andersen et al., 2017; Skov et al., 2015). Cardiac-remote-monitoring patients and their relatives have also experienced identity change and influences on behavior and social interaction, which were highly related to the disease and symptoms rather than the monitoring (Andersen et al., 2017). However, the existent or suspected health condition or disease does additionally determine the quality of monitoring, for example, duration or frequency. Therefore those also influence the patient experience of, and through, the monitoring (Grönvall & Verdezoto, 2013).

Treatment and healthcare processes have an influence on patient experience (Opel & Hart-Davidson, 2017). Evaluating the satisfaction or other factors in the healthcare process is a major subject of patient-experience research in general (Wolf et al., 2014). Clinicians, especially in long-term care relationships, are major influencers (Andersen et al., 2017). For example, patients have experienced expectations from or towards clinicians. When due to self-monitoring, they have had more responsibility for their own treatment and felt guilty about not fulfilling the expectations set for them. On the other hand, they have expected more feedback, understanding, and sympathy from clinicians.

3.2.3. Role of information in patient experience

Multiple studies have recognized patients' need for information (Adams & Blandford, 2005; Andersen et al., 2017; Skov et al., 2015). This was often related to the symptoms and disease, sometimes also the process of healthcare or monitoring.

A lack of information was noticed by multiple studies. Some studies have reported that the lack of information has caused anxiety and uncertainty for patients during home-

monitoring, and vice versa, information reduces those (Andersen et al., 2017; Grönvall & Verdezoto, 2013; Skov et al., 2015). For example, a standard design in cardiological home-monitoring is that clinicians engage with patients only in the case of alarms (Andersen et al., 2017; Skov et al., 2015). The lack of feedback made some Skov's (et al.) participants anxious about whether the monitor functions properly. However, it was not the only source of anxiety, and nevertheless, most participants were satisfied with the monitoring without feedback (Skov et al., 2015). In addition to the performance of the monitoring, Andersen et al. (2017) reported negative experiences of being uninformed about the patient's own condition or treatment and relief when being informed on those, although the information would be confirmation of the illness.

3.3. Summary and reflection on previous work

Considering the relevance of this research, the importance of information for patients examined with home-monitoring technologies is underlined in prior research. However, there are also examples of how the patient's unwillingness to think about his or her illness causes satisfaction with not being informed. The needs for information consider various things like the illness or symptoms related to it, or the monitoring and healthcare process. These findings emphasize the need for the patient tutorial of Nelli and this user research, which aims at providing information for the design of the tutorial content. The information needs in the context of Nelli require attention in the data gathering in order to make the content meet the needs of users.

Previous work also shows the importance of understanding the context of each monitoring system because patients' experiences are influenced by multiple factors, for instance, their medical condition and the severity of it. Patient experience is not isolated, nor is the user experience. In addition, the aspect of examination as a service and the user's perspective to the service process is scarcely investigated. Therefore, the successful research of them requires a broad perspective; for instance, careful follow-up questions in the interviews about issues not directly related to the examination.

As written earlier, these questions are addressed by investigating patient experience, focusing on, but not limiting to, user experience, in the context of Nelli examination. Patient experience lacks an established definition in the literature. Here it is used in the meaning of *patient's experiences, before, when, and after the patient undergoes/went an episode of care*. User experience follows the definition of ISO standard: *"user's perceptions and responses that result from the use and/or anticipated use of a system, product or service"* (International Organization for Standardization, 2019).

4. Studying the patient experience of Nelli examination

This chapter presents the process and methodology of the user study of the Nelli examination done for this research. A qualitative approach was chosen because of the limited number of patients who had been examined with the Nelli examination and, further, potential participants for this research. The user study was based on semi-structured interviews of seven participants. In addition, key contact points, i.e., installing and uninstalling Nelli PRU, were observed, and other materials like email conversations and photographs were gathered in the case of one participant. Multiple methods were used in order to broaden and deepen the possibilities to gather data with a small number of participants. The results were analyzed with inductive qualitative data analysis following grounded theory with the aim of gaining an understanding of the experiences of the users.

4.1. Participants

As explained before, a remarkable share of the examined patients are not themselves using the device, but rather their caretakers are. Therefore, the sampling of this research includes both patients and their caretakers. The sampling of seven participants covers different types of caretakers and patients. Two of the participants are patients (P3, P5), four parents of patients (P1, P2, P4m, P4f), and one is a nurse in a nursing home where a patient lives (P6). The sampling covers cases of six patients, of which three are adults with intellectual disabilities and need continuous support (P1, P2, P6), one is a 6-year-old child (P4), one is an independent adult (P5), and one lives in a supported living unit and lived at home with family during some of the examinations referred to in this study (P3).

The following table (Figure 5) presents participants' description and their role (patient or caretaker), their living conditions during the examinations, their sex, and how many times they had been examined with Nelli at the time when the interviews were done. The number of examinations is told in order to see if the participant is a first-timer or more experienced user and enable a comparison of findings based on that.

The participants were recruited among patients or their caretakers who had previously given consent for using their data for product development purposes for NEL and who had had an examination within six months before the interviews. However, for this research, a new consent was asked (Appendix 1). Based on these criteria, a list of ten candidates was made by NEL. These candidates were contacted and invited to participate in the user research. Five participants from that list accepted the invitation, and one case expanded to two participants because both parents of the patient were interviewed. In addition, one participant was recruited among the patients who had an examination during the time of the user-research, in order to observe the predictable contact points (installing and uninstalling) of the service process.

Participant	Role/Description of participant/(age)	Living conditions of the patient during EXAMs	Number of EXAMs
P1 (male)	Father of an adult patient with intellectual disabilities	Home with parents	2
P2 (female)	Mother (age 59) of an adult patient (27) with intellectual disabilities	Home with a parent	2
P3 (male)	Patient (24)	Supported living unit / home with parents and brother during earlier examinations	4
P4m (female)	Mother (34) of a child (6) patient	Home with parents	1
P4f (male)	Father (40) of a child (6) patient		
P5 (male) *	Patient (63)	Home with a spouse	3
P6 (female)	Nurse (23) in a nursing home where the patient lives in.	A nursing home, continu-ous support	1

Figure 5: Table of participants (* In addition to interviewing, in the case of P5, the installation and uninstallation of the system were observed)

4.2. Data collection

The main method of data collection was interviewing. The main contact points of the service process (installing and uninstalling) were observed in the case of one participant. In addition, other materials, including e-mail discussions, photographs, and hand-drawn user-journey maps drawn together with the interviewer and the participants during the interview, were gathered.

The user research included seven interviews. All of the participants were interviewed. Five of the interviews were done face-to-face in a patient's home (P1, P4m, P4f, P5), or a nursing home (P6), one as a phone interview (P2), and one with a Skype video call (P3). In the case of P4, both parents of the patient (P4m and P4f) were interviewed together, at the same time.

The interviews were semi-structured. Follow-up questions on themes that emerged during the interviews were asked actively, and interviews were allowed to progress also towards themes that were not planned ahead, nevertheless also inquiring the pre-set themes and questions. Therefore, the outcome of the interviews also contained different topics than pre-planned questions. The duration of the interviews varied from 39 minutes

to 1 hour 15 minutes. Interviews were recorded, and hand-written or typed notes were made during them. The recording of P1 failed, and only part of the interview was captured. Because of well-kept notes, P1 was nevertheless included in the research data. Interviews were transcribed verbatim, excluding the interview of P1, which had a failure in the recording.

During the interviews which were done face-to-face, journey maps of the patients' user journeys were drawn with pen and paper, partly as a (visual) note, partly in order to help the participant to recall the order of things, and to make sure there is a common understanding between the participant and the interviewer of the described order of events. These were later, together with other user-research data, combined as general user-journey maps of the patients' process.

4.3. Data analysis

User-research data were analyzed using qualitative data analysis (QDA). The qualitative research approach was based on grounded theory (GT) in a wide sense of the term (Blandford et al., 2016, p. 55). That is to say, the detailed coding-process-structure of the GT originally presented by Glaser and Strauss (1967), was not used; however, an inductive ("bottom-up" or "grounded" in data) QDA-approach typical in HTI was (Blandford et al., 2016, p. 69; Lazar et al., 2017, p. 305). According to Lazar et al. (2017, p. 306), the GT method generally includes *open coding, development of concepts, grouping concepts into categories,* and *formation of theory*. Blandford et al. (2016, p. 70) describe *interleaving of data gathering and analysis, avoiding pre- expectations, theoretical sampling,* and *theory building from data through comparative analysis* as the common ground of different variations of GT. These worked as basis and guidelines for my approach; however, in the scope of a master's thesis, the application of some of these elements remains lighter than in a full-scale grounded theory approach.

Due to the pragmatic goals of this research, also the approach to data-analysis methods focused on aspects with potential design implications. The user-research data (i.e., transcribed interviews and notes, hand-drawn journey maps, observation notes, e-mails, and pictures) was coded following grounded theory and emergent coding, as presented by Lazar et al. (2017, pp 304–308). In emergent coding, interesting concepts or ideas are first noted from the material, naming them using *codes* that emerge from the data. The purpose of this open initial coding is to do the QDA without any theory or a model guiding the analysis (Lazar et al., 2017, pp. 304–305). After the initial coding, codes that represent similar contents were grouped together under the same conceptual heading (Corbin & Strauss, 2014, p. 7). Concepts were derived from the data while doing the data analysis in order to represent the data. By further analysis, the concepts were developed as categories and core categories and, eventually, theory statements.

During the process of analysis, some of the initial codes were renamed or redefined, split into multiple sub-codes, or gathered under upper-level codes. The codes described different types of data, e.g., background information or context, themes the data represents, or dimensions of the data. A digital tool, ATLAS.ti, was used in the QDA.

4.4. Ethical considerations

User research of medical self-monitoring requires careful ethical consideration. Not only is the gathered data containing information about patients' state of health, and therefore is highly delicate, but also the interviewing and already the recruitment of participants penetrates into people's private sphere of sensitive matters.

The recruitment was planned together with Neuro Event Labs. The candidates had previously given consent for using their data for product development purposes for NEL. This lowered the risk of intrusiveness in contacting people considering their medical information. Also, the recruitment calls were planned in order to ensure their discreetness. Obviously, participation was voluntary, which was emphasized in the recruitment. Some potential participants canceled, slightly apologetic, which was replied with reassurances that it is definitely allowed and even suitable if they feel like doing so. Consent for this research was obtained from each participant.

Because the interviews considered sensitive and private matters of participants, the delicacy was emphasized; however, many participants themselves brought sensitive matters into the discussion. Voluntariness was the key-principle in the interviews.

Gathered data were saved in password-protected data storages and in locked or supervised locations until they were destroyed after the research was finished. As stated in the consent, the results were reported anonymous and, in the way, that single participants cannot be recognized. In some cases, this required omitting citations, removing recognizable contents like names or locations, or presenting some findings in a manner that it was not directly connected to a certain participant, just to make sure anonymity was not compromised.

5. Findings of the user research

In this chapter, I present the findings of the patient experience research of the Nelli examination. First, I present the emerged themes related to the primary research question about the users' experiences of the home-use of the Nelli examination. In addition, user research revealed users' needs and motivations. Due to the bottom-up approach, themes of some of the pre-set sub-questions were diminished during the study, and therefore they are not presented on a thematical or topical level in the findings. However, findings related to them are included under the emerged themes. Second, I explain how patients or their caretakers experience their journey as a user of the Nelli examination in temporal dimensions and visualize it in the form of a journey map.

5.1. Elements of patient and user experience of Nelli examination

This section answers the primary research question and presents found categories and concepts related to how patients or their caretakers experience the use of the Nelli examination. First are presented the general user experience aspects of Nelli, that is to say, themes more connected to the actual use of the device or the service process. From those, I move towards characteristic themes of Nelli examination or medical home-monitoring in general. This division is done for the sake of clarity in presenting the results; however, separating these factors from each other is not supported by the findings. One of the found themes, which will be presented in Subsection 5.1.6, was that the experiences of patients or their caretakers are highly influenced by extra-use factors.

5.1.1. Experiences of the use of the device and the service were mainly positive

Participants described their overall experiences of the service with positive attributes. The overall experience means here the high-level experiences of the Nelli examination, including comprehensively the examination concept, technology, device, service, and process. Reasons varied.

Typically, the examination concept was considered good and relatively convenient. P3 and P4(m/f) compared the Nelli examination to video-EEG or other examinations and regarded that Nelli allows living "humane life" in "everyday circumstances" (P3). However, P4m said she had some doubts about the accuracy compared to V-EEG. Especially the possibility to do the examination at home was valued:

> "It is more comfortable when it is just there, at home, at nights. You can be, go and do things of your own life. So, there ain't nothing to it. As I said, I'd rather have it again, if it is offered." (P4f)

Participants did not mention any major problems which would have turned the overall experience negative; however, the examination has downsides (e.g., privacy issues),

which users are willing to accept in order to achieve the benefits. This theme is discussed further later in Subsection 5.1.2.

> "At least there are more plusses than minuses, so whoever has started to develop this has had a good idea." (P4f)

Comments considering usability were mainly positive. The use of the device was regarded as easy. Most participants were inured to the device during the examination period:

> "After a week or two, I did not even remember them (cameras)" (P2)

However, the parents of a child patient (P4m/f) told the patient was annoyed with the device and cried because of it "almost every night" (P4m). In their case, examination time was only two weeks, as it usually is four weeks. This might have reduced the possibility of getting inured to the device. The mother also said the patient is very sensitive towards new things.

As minor problems, some of the participants mentioned some annoyances or usability problems in the device, like cyclically glowing light, "whirling sound" (P5), unnecessary buttons in remote control, and narrow operating sector of the remote control. Although participants said they were not bothered by those, those are nevertheless reported as minor problems.

The physical presence of the device with its stand caused some problems or questions to solve when finding a suitable place for it (P4), cleaning (P1), or keeping the device unmoved from its location (P4, P6). The nurse (P6) said in the interview that in their nursing home, the inhabitants are overly "interested in everything new," which created a need to build barriers for the device from the furniture. Despite the barrier, the camera of the device was turned towards the roof during the examination period. This was noticed and informed to the nursing home by NEL. Overall, the support calls in case of problems or data-quality issues were valued, in some cases, highly:

> "I feel myself important because they really work for this, and not just leave it (the camera) there to roll." (P3)

The service process conducted by NEL was described most parts good or at least working and not problematic: "It works like a Buick." (P5) However, this should not be considered congruent with the total healthcare process of getting to the examination and getting the results of it, neither the experience of that process. From a patient's perspective, this division is not always clear or even relevant; therefore, the experiences related to them are influencing each other. In the case of some participants (P2, P4, P5), their process with healthcare or treatment influenced their experience of the service process, or they were not entirely happy with the process and were unclear about the division of

responsibilities in the process. One aspect of this issue is the lack of information, which has its own theme written in Subsection 5.1.3. The experiences of the service process are described more detailed in the findings of the user journey in Section 5.2.

5.1.2. Privacy concerns influenced behavior; clinical purposes made it accepted

Having video and audio recording at home and sending the data forward would break the normal boundaries of privacy of almost every participant. However, this is accepted due to the purpose and context of clinical medicine and personal treatment. In addition, getting inured to the examination mitigates privacy concerns. Privacy issues caused behavioral effects, as an answer to the sub-question (C) of the research question; however they were accepted because of the clinical purposes of the examination.

Typical subjects of the privacy concerns were, for instance, someone outsider hearing private discussions (P1, P2, P3, P5, P6) or being dressed revealing in front of the camera (P1, P2, P3, P5):

> "We tried not to discuss too loud about things (*pause*) and had more clothes on. Not always, though." (P1)

P2 also mentioned snoring or other sounds made while sleeping in the same room as the patient. Those were associated with the feeling of shame.

Only in the case of P4, the parents did not show concerns about privacy:

> "He has his own room, our voice (or sounds) do not reach there. Or, if it does, it does not shake our world." (P4m)

Instead, they told that they had used their own IP-camera, acknowledging the possibility that "someone could have hijacked the signal of it," nevertheless being not worried about the situation. (P4f)

Privacy concerns caused pressure for participants (P1, P2, P3, P6) to change their behavior from their normal in their homes. For example, P3 went to the bathroom to change his underwear, and P2 felt pressure to change the way she talks and dresses.

> "Of course, I thought that I'd need to tidy my vocabulary (*laughter*), and otherwise as well, I could not jump around like normal, like without clothes after having a shower or anything else like that." (P2)

However, all of them described the actual changes in their behavior minor or non-existent or that they experienced them tenuous or were not bothered by them. They all described they were inured to the recording and the device.

In some cases, the privacy concerns extended to other people than participants themselves. P3 said he finds it important that the cameras are positioned so that, for example, family members do not have to be reluctantly recorded. When saying this, he referred to the time when he lived at home with his parents and brother. In addition to night cameras,

he had had daytime cameras, which makes this issue more relevant. He had also been examined with Nelli in a supported living unit where he lived during the interview. He said he had noticed there that nurses who bring him his medicine did not spend as much time to discuss with him during the examination as they normally did. When he spoke on the phone with friends, he wanted to inform them about the recording. Similarly, P2 had told her friends who visited her about the recording and told them to avoid coarse language and sensitive topics.

Privacy concerns or issues were considered as a downside of the Nelli examination; however, they were overcome by the benefits of it. Clinical purposes and benefits for patient's health or treatment were seen as the major motivators of having the examination despite the downsides:

> "I call these Big Brother. – – nevertheless, one has to be dumb if one would not want these." (P2)

The perspective of nursing staff on privacy showed different issues. The nurse's (P6) experiences were related to her work, and privacy concerns related to the feeling of her work is being evaluated. Shame was also associated with the nurse's experiences when she thought some activities might seem worse in the video than they are in real life. She said that among the nurses in their nursing home, it was unclear who can see the video.

5.1.3. Lack of information caused negative experiences

The second major theme of negative experiences was a *lack of information*. This is partially answering the sub-question (B) about the role of information in patients' experiences. Five participants (P2, P4m/f, P5, P6) mentioned problems related to the lack of information. The remaining two participants (P1, P3) mentioned things they or other relevant people did not know about the examination; however, they did not think those caused any problems.

Participants experienced a lack of information in different areas. In data analysis, the main category of lack of information was formed from five different sub-categories, which categorize the areas of which the information was missing (Figure 6). Three of these areas are related to how the examination, including the service related to it, works: *the use of the devices and preparations for it*, *service process,* and *criteria and principles of the examination*. One area is about *the outcome of the examination*: the form of the results and can patients see them? One area is related to *privacy*: it was unclear and problematic for some participants, who can see the data? These sub-categories are not exclusive: one comment or fragment of data can belong to multiple sub-categories.

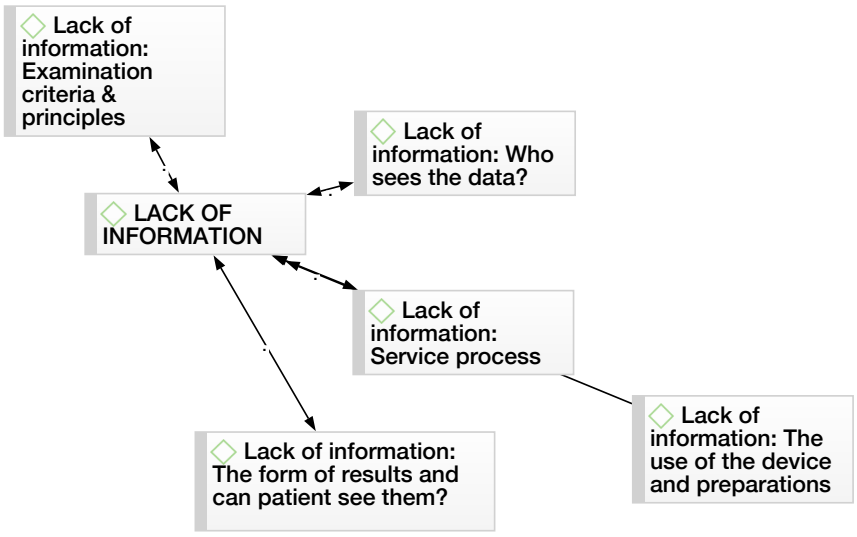


Figure 6: The lack of information consisted of five sub-categories.

Lacking information on the use of the device and preparations before the examination caused P2 and P4 (m/f) to experience stress and excessive work. For instance, P4m said they cleaned the wrong place because they did not know what the size of the device is and where it should be located.

For five participants (P1, P4m/f, P5, P6), the service process was unclear. For instance, the division of responsibilities between the hospital and service provider (NEL) was not known. However, it did not cause problems for the examination or the service process, but rather an unclarity about whom to contact in case of potential questions. As a consequence, it was unclear was the reason for the long waiting time of the results of the examination, in the service provider or the hospital.

P4 (m/f) and P5 were interested in the functioning principles of the examination and the criteria by which it detects the seizures. This information they had been unable to receive by the time of the interviews. This is partly connected to the outcome of the examination: for some participants going through the results of the examination with the doctor also clarified the questions related to the examination criteria and principles because those were explained by the doctor. On the other hand, it is dependable on the doctor what results are shown to the patient and how they are shown. This also includes information about what kind of outcome the examination offers. Typically, participants did not know what kind of outcome there is before they went through the results. For instance, some participants (P3, P5) acclaimed a visualization of seizures and epileptic activities, which is provided for the doctor as an outcome of the examination (Figure 7), while some had not heard about it. P5 found out about it after his second examination period and considered it something he wants to see again next time:

"I think that next time I want to go through those balls with the doctor. – – First time, (when) we went through the outcome, (s)he just told me. I did not even know there is that kind of graphics!" (P5)

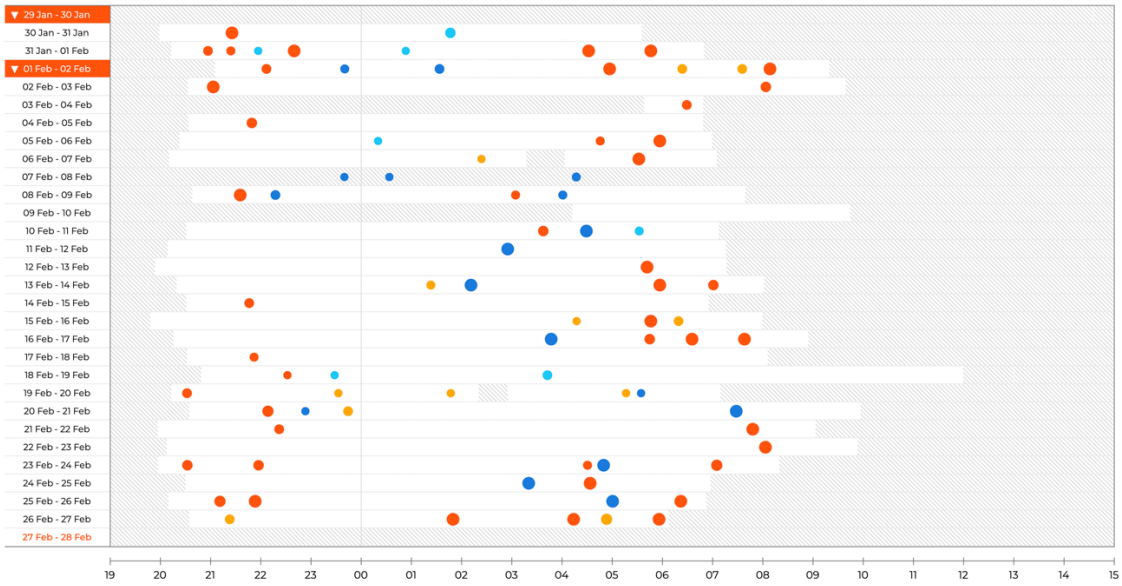


Figure 7: Example view of the doctor's user interface, which shows an overview of the results of the Nelli examination. (Published with permission of NEL)

Three participants (P1, P4m, P6) had questions related to who can see the data. For P1, it was unclear what the service provider does with the data; P4m was not sure can they see the data themselves, and P6 (nurse) did not know if, for instance, the mother of the patient can see the videos where she and her colleagues work.

When investigated temporally, the lack of information was related to different parts of the service process. However, there was an emphasis on lacking the pre-use information or other information whose need typically begins before the examination period (Figure 8).

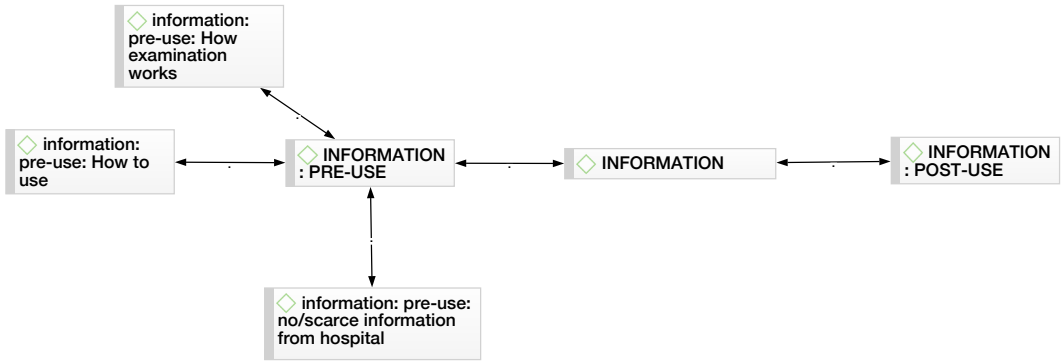


Figure 8: The lack of information was emphasized in the case of the information needed before the examination period.

For P4 (m/f), it was unclear before the examination how to prepare for the examination, how long the examination period is, how does the examination work, and what data they can see as an outcome of the examination. This was a good example of the lack of pre-use information. In their case, it is worthwhile to mention that their examination was the first time Nelli examination was used in the pediatric neurology unit where the patient was treated in, and therefore the doctors had scarce information about the examination. Therefore P4 (m/f) experienced having insufficient pre-use information. However, it emphasizes the dependence of doctors in providing the pre-use information in the current state of informing about the Nelli examination.

Information was also needed during and after the examination period. However, participants did not experience the lack of it, or they got an answer to their needs through support, which was highly appreciated.

A relevant finding considering the product development, although not as reliable than other reported findings, was that participants seemed not to be aware of the things potentially interfering with the examination, for instance, sounds or movement of others than the patient. This was mentioned directly by only one participant (P1) and indirect by two more (P2 and P4). This was discovered in the interviews when discussing concerns about caretakers' presence in video or audio recording. The interviewer asked to clarify did they mean concerns about interfering with the examination by their presence or privacy issues, and all of them (P1, P2, P4) answered privacy issues. P1 also clearly mentioned that he did not even think about if they could interfere with the examination somehow.

5.1.4. Users' needs direct their experiences

The user-research revealed the *needs* of patients or their caretakers, as users of Nelli. The needs of users are essential necessities of users, especially considering their situation as patients or patient's caretaker. Figure 9 shows the category of needs divided into separate concepts of needs. However, the list should not be interpreted as a comprehensive list of users' needs, but rather as the ones that appeared in the user research. They are described high-level, they are interconnected, and they serve as a background for understanding the users, and further for designing the patient-tutorial.

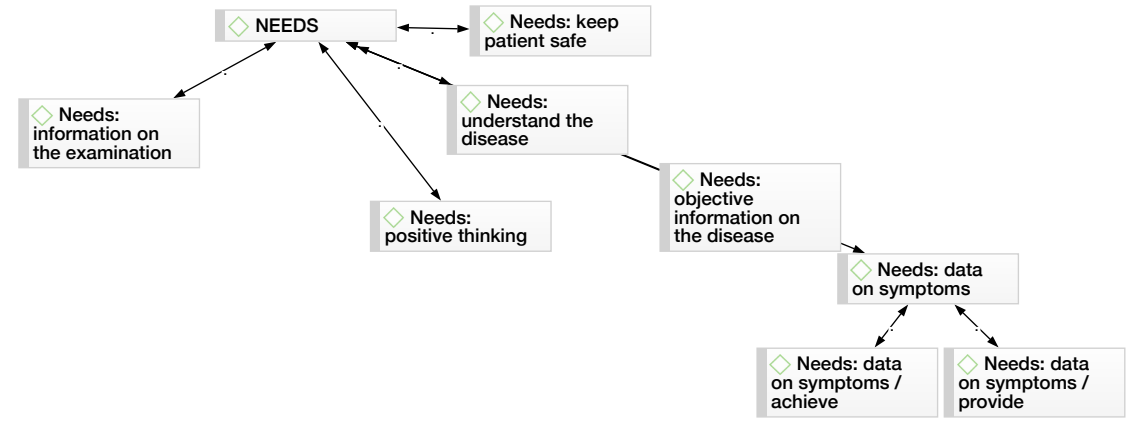


Figure 9: Categories of needs.

These concepts of needs are extracted from user-research data; however, most of the data related to them was not direct expressions the need. The concepts required interpretation: most needs were expressed directly in the interviews at least once, and the indirect expressions support the concept. In three of the concepts, the most direct expressions were spontaneous improvement suggestions from the participants during the interviews.

The safety of the patient is a fundamental need in this context. It is obviously at the core of the whole treatment process; however, the context of the data gathered in this research is narrower. The comments categorized under this need are related to the seizures, their severity, their consequences, the care during them, and their treatment. Directly this need was expressed by participants who are parents of patients (P2, P4m/f). Participants' goals related to this need are to "keep epilepsy (seizures) away" (P2), which eventually means getting the right treatment (P2, P4m/f), or when the seizures occur, do the correct actions to ensure the safety of the patient during them (P4m/f, P2).

> "Because it (seizure) always comes when he sleeps – – can we sleep without concerns or not? Do we wake up for sure, if the seizure turns worse?" (P4m)

For the participants who expressed this need in the interviews, it was high in priority. They also described the history of the patient's disease and its treatment: both patients had had severe seizures and treatment changes, which first turned the symptoms worse, and after that, better. This had caused concern in parents, which can be an explanation for emphasizing the need to keep the patient safe in the interviews more than other participants. P4f also expressed their wish to have a seizure alarm system and suggested it as an improvement for the Nelli examination. Similar improvement suggestions were also suggested by P3 and P6.

As visualized in Figure 9, the need to understand the disease, the need for objective information on the disease, and the need for data on symptoms are interconnected. The

need to understand the disease refers to the participant's inner need to perceive information about epilepsy in general and especially of their own case and condition. P3, P4m/f, and P5 expressed this need in the interviews. P1 and P2 showed they had gained a significant amount of information, probably due to longer history with the diagnosis. This might suggest that they had the same need already satisfied; however, this was not directly expressed during this research. This need had various goals related to it. For P4m, it was connected to the need to keep the patient safe. In order to pursue that as her major goal, she needed to understand the disease. For P3, understanding the disease helped him to find positive thinking, which also was his need. Of all the participants, P5 was emphasizing this need the most. He showed signs of being data-oriented throughout the interview and the observations:

> "Then if (I) would get the results for myself as a recording, so I could compare and ponder – – if some things correlate." (P5)

He was hoping to find information on the symptoms and the criteria of how the examination detects the symptoms; however, he lacked that during his third examination period, which was during the interview. As reasons for this interest, in addition to curiosity, he mentioned that if he or his spouse could recognize the correct symptoms, they could observe and provide the information needed for treatment for doctors between the examinations:

> P5: "It has kind of begun to interest me, how this monitoring could be done in a light manner by another person, and every now and then these more accurate (examinations). I mean exactly that when there is a change in medication, there can be half a year between the examinations, and nevertheless, they (doctors) think if the medication has had any impact. I say that I have not noticed anything, or I have noticed, but…"
>
> Interviewer: "Do you mean that you do not know what to observe?"
>
> P5: "Yes."

As a major reason for the need for objective information on the disease, participants described a connection to the information needed in their treatment. It is partly connected to participants themselves understanding the disease (P4m); however, in most cases, participants (P1, P3, P4m/f) felt that observation-based monitoring of seizures or other symptoms was subjective and not accurate. P1, P3, and P4f experienced the Nelli examination positive answer to this need.

> "I was positively surprised when we looked at the results with the doctor. Before that, everything has been dependent on notes, and everything is subjective, what people see, hear, or pay attention to." (P1)

P3 felt that Nelli removes a burden of proof which he felt he had when he needed to describe symptoms or seizures to healthcare personnel based on self-monitoring or notes:

> "There is that good side in the cameras, that you don't need to argue with them. –
> – It records everything." (P3)

P4m had doubts if Nelli was accurate enough or recognized the seizures of their "not-a-textbook-case patient." However, she shared the need for objectivity and thought Nelli was a good examination when it was in their case done after V-EEG. In her opinion, these together were answering the need for objective information, and Nelli served the need, especially with its longer examination period.

The concept of the need for data on symptoms is divided into two parts (Figure 10). The need for data to exist is common to them. About the direction of the way the data needs to flow, or who should perceive it, two opinions were presented: first, the patients achieving the data, or second, the patients providing the data for the doctors. These opinions were nevertheless presented by the same participants (P3, P4m, P5).

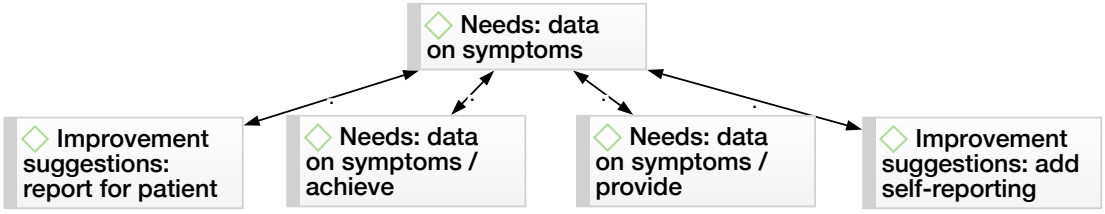


Figure 10: The need for data on symptoms expressed two directions of the data flow: achieving (left) and providing (right) the data.

One side of the need is interconnected to the need to understand the disease, the need to keep the patient safe, and the need for positive thinking, which creates a demand for data on the symptoms in general and the symptoms of the particular patient. As examples of the user-research data where this side was expressed are spontaneous improvement suggestions of a report of the results for the patients (P4m, P5).

Another side refers to the data needed for the treatment. Acquiring this data was a general motivator for the examination overall. P5 was, in addition, remarkably interested in providing observed data on the symptoms for his doctor. One reason for that was that his doctor had previously asked him or his wife about observed symptoms. He described "maximizing benefits" of all examinations and treatment as his motivation to do this.

Separate from other needs, however relevant for the development of the Nelli examination and the patient tutorial of it, was the need for information on the examination. P3, P4, P5, and P6 showed interest and need for information considering the examination. For P4, P5, and P6, the need had remained unanswered during the interviews. The information they needed was related to the principles and criteria of the Nelli examination, the

service process and practicalities related to it, and the division of responsibilities in providing the Nelli examination. P1 had some questions about the examination; however, it was not a strong indicator of this need. P2 seemed not interested in the functionality of the device nor the service process, except for the minimum instructions for use. However, she was a demanding caretaker, and for her, it was important to, if not to get informed, at least to trust the examination.

5.1.5. Motivations: experienced benefits overcome downsides

The user research revealed personally meaningful factors or reasons for using the examination or for overcoming the downsides of it. In this research, those are called *motivations,* and they are described in Figure 11. Different motivations are not exclusive. The same participants had several motivations.

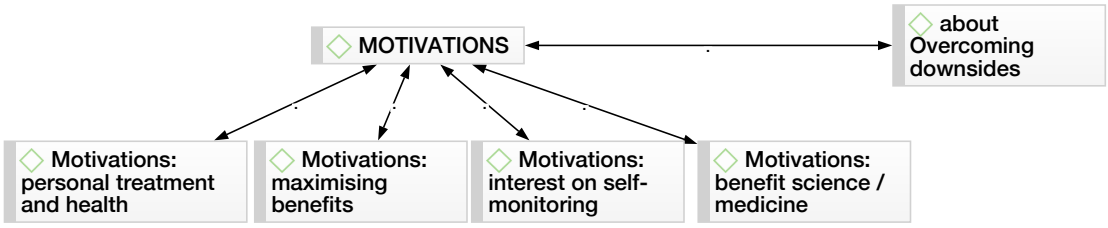


Figure 11: Four types of motivations worked as reasons to use the Nelli examination and to overcome its downsides.

Experience of compromised privacy was mentioned previously in this chapter as the major downside of the Nelli examination. Other examples of minor downsides could be extra work or trouble, or changes to normal life caused by the examination; however, these were not emphasized in the interviews. These motivations presented here are the reasons participants mentioned for overcoming those downsides.

Benefits for the patient's personal treatment and health was the major motivation among the participants. It motivated patients, or family members of patients, to use the Nelli examination and to overcome the downsides if they experienced some.

> "I would not mind even if we had a camera in the toilet if it would be because of us having some sort of improvement for this life. – – I hate everything useless: if we'd have, let's say, Big Brother cameras, they would get the heck out of here (*laughter*) and fast! But this (camera of Nelli examination) was for this sort of thing that life kind of depends on." (P2)

P5 described the overcoming of disturbance and compromising privacy in the following words:

> "Well, let's say you need to have the right attitude, like it is a good thing that those things exist and that they bring those." (P5)

He highly valued the data that was acquired with Nelli. Further, he wanted to learn more about recognizing symptoms in order to make notes of them, because he was motivated by “maximizing the benefits” of the examination. He also mentioned, directly and indirectly, his interest in self-monitoring as a motivation.

Two of the participants (P1, P3) also found extra-motivation from availing science or medicine. P3 referred to allowing his examination data to be used for developing the Nelli examination and its algorithm because he wanted it to benefit others as well.

Further investigated, the experienced benefits of the Nelli examination can be included as secondary motivations. They are also associated with overcoming the downsides of Nelli. In Figure 12 are presented the benefits which the participants expressed in the interviews.

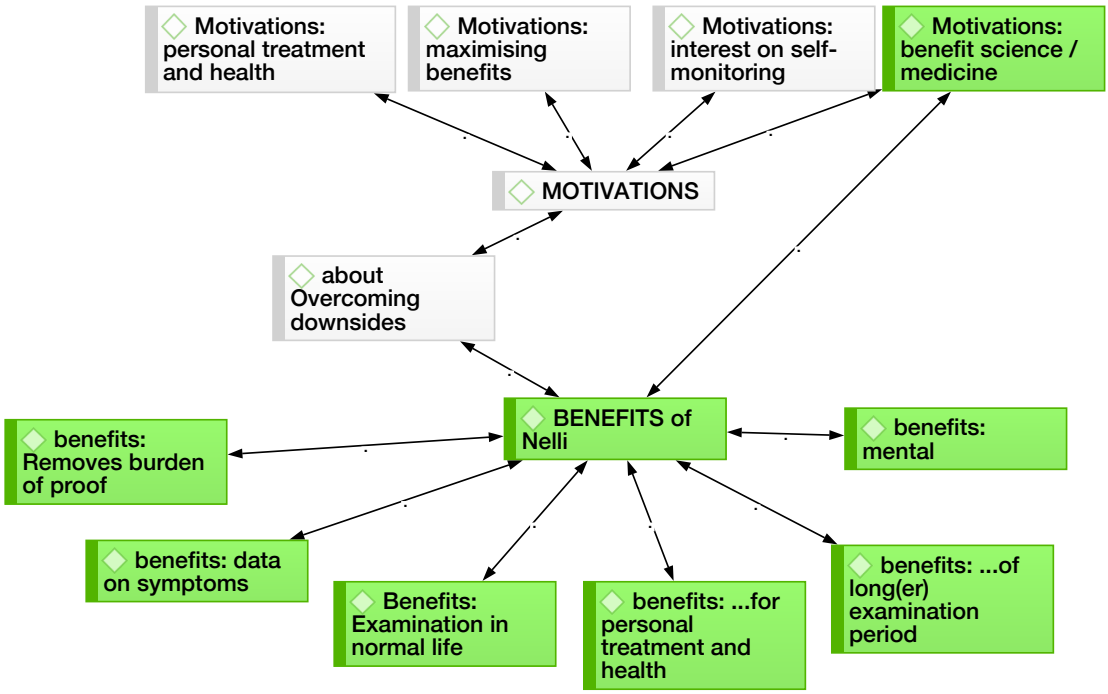


Figure 12: The benefits of Nelli (green color) motivate users for the use of Nelli and to overcome the downsides of it.

Briefly explained, participants mentioned the following things as benefits of Nelli once or several times. It removes the burden of proof from patients or their caretakers by giving objective information on the seizures or other symptoms (P1, P2, P3). This is associated with mental benefits (P3). It can be done in relatively normal living circumstances, especially when compared to V-EEG (P3, P4f). In addition, it has a longer examination period than V-EEG (P3, P4f). As mentioned before, it has benefits for patient’s personal treatment and health (P1, P2, P3, P4m/f, P5), and medical science (P3).

5.1.6. Patient experience is influenced by extra-use factors: patient's history with epilepsy, the treatment of it, and the healthcare process

Based on the user-research data, the user experience of patients or their caretakers is influenced by extra-use factors. Some examples of these factors are presented here. However, their causalities are not thoroughly investigated, but the rather loose correlation is shown, and it should not be considered as a comprehensive list.

Every patient or a family member of a patient explained in the interviews their experiences of the use or the service process of Nelli with a longer history than their first contacts with Nelli. A simple form of this was a comparison of Nelli to other examinations (e.g., V-EEG: P3, P4m/f) or self-reporting (P1, P2, P3).

The patient's history with epilepsy and their treatment of it seemed to influence attitude and experiences related to Nelli. P2, P3, and P4m/f mentioned treatment changes, which had caused changes in the symptoms and seizures, sometimes worse, sometimes better. As a result, they valued the examination and monitoring of the symptoms highly. In addition, they had high expectations. P4m/f also expressed doubts about the accuracy of Nelli. P4f explained that their doctors had told them the patient is a "not-a-textbook case."

> "(hospital name is hidden) have denied us alarm-mattresses and all this kind of epilepsy seizure-alarm systems, because they do not work in that kind of (epilepsy). – – We have wanted those, but in (hospital), they said that it does not work with that. That there would be constantly false alarms or that it does not recognize them." (P4f)

P2 had experienced difficulties in getting treatment for her son in their home district.

> "(city/hospital name A hidden) does not recommend any treatment for persons with profound intellectual disabilities, but I myself repeatedly demanded that we could go to (city/hospital name B hidden). – – They do not treat any disabled here! By intimidation, I got us to (city/hospital name 2 hidden). Here you need to use heavy words to get (treatment). You need to bring up parity laws (Finnish: *yhdenvertaisuuslaki*) to get treatment." (P2)

After P2's son got his treatment in a hospital in another district, she experienced they had good examinations and treatment, which had also eventually led to better results and fewer seizures. Nelli examination was prescribed there and was part of this treatment, which was experienced highly positive after highly negative experiences. Therefore, it should be recognized as a potential source of false-positive results considering the user experience of Nelli.

P5's diagnosis was relatively new during the interviews: he was 63 years old and had had the epilepsy diagnosis two years earlier. It had made him inquisitive considering epilepsy, which further influenced his experiences as a user of Nelli in a way that he highly valued that Nelli provided him data. However, he would have wanted more information than was available about the examination itself.

5.2. The user journey of Nelli examination

The user journeys of patients were investigated in order to understand the examination and service process from a patients' perspective, and to answer Sub-question (A), what does the user journey of patients or their caretakers consist of? Because the Nelli examination is implemented as a service, and the service process has temporal dimensions, investigating user experience temporally was justified. It was used to inform the content design of the patient tutorial, for instance, by pointing out problem areas or needs for information.

Participants' individual journeys were inquired in the interviews. In those interviews which were done face-to-face, the user journey was also visualized with pen and paper. They were reviewed together with the participants during the interview, in order to make sure the interviewer understood the user journey correctly. These visual notes were later used to combine the individual user journeys as a summary and a model of a typical user journey. When inquiring about the individual user journeys, the first focus was in all kinds of contact points between the Nelli examination and the participants, including one-sided information change, for example, reading about Nelli from social media. Temporal dimensions were inquired, starting from the first time when a participant had heard about the Nelli examination and ending to potential events after receiving the results from the doctor. All contact points, use events, problems, and highlights between those were inquired.

In addition to the participants' perspective, the service process was inquired from the service provider, Neuro Event Labs (NEL). Based on that, it was known that Nelli is prescribed and ordered from NEL by doctor or hospital. After that, the NEL installer books a time for installing and installs the personal recording unit (PRU). A user guide, an A4-sized paper sheet, is given for the user (Appendix 2). The examination period lasts typically four weeks, during which the user has to switch the device on when the patient goes to sleep and off when the patient gets up from the bed. If the patient is away for nights, NEL should be informed. No other contacts are needed unless some problems occur. A phone number is provided in the user guide. PRU sends the data to a cloud automatically, and data-analysis begins. When the examination period is at its end, the installer books a time for uninstalling and picks up the device. The analysis is finished by NEL, and the report sent to the doctor or hospital, who prescribed the examination. This

initial view of the service process from the service providers' perspective is described in Figure 13.

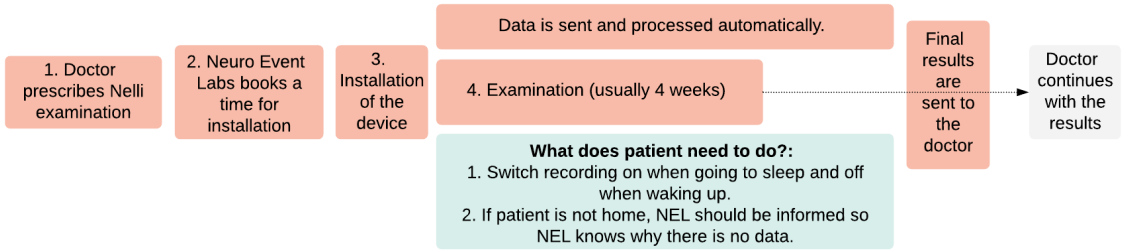


Figure 13: The service process from the service provider's perspective.

The service provider's perspective was inquired before planning the interviews in order to understand the process. However, when interviewing, participants were let to explain themselves the process from their perspective and own words.

For most parts, participants' descriptions followed the service provider's perspective. This can be seen in a visualization of the codes and concepts made in data-analysis, arranged in the order of their described appearance (Figure 14).

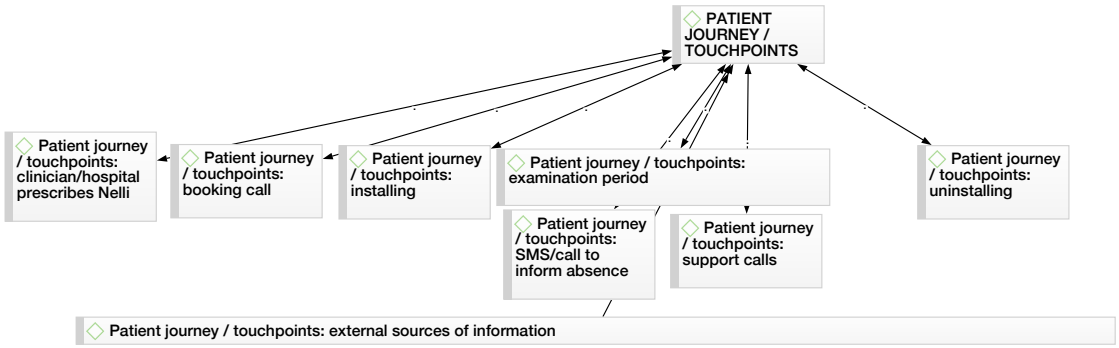


Figure 14: The main elements of participants' descriptions of their user-journey touchpoints mostly follow service providers' description.

However, some exceptions existed. In the case of P4, the examination period was two weeks instead of the typical four weeks. P2 and P3 had had multiple cameras. In the case of P2, one camera was in bed for night-time use and one in the living room for daytime naps. On their first examination, she was also asked to make notes on the seizures and send them to NEL. After the first examination of P3, he had had an additional daytime camera in the living room, which was used while he was awake. These exceptions were usually related to clinical purposes and initiated by the doctor or the hospital in charge of the treatment.

Participants were also asked about their experiences during the process. Concepts described in Figure 15 were formed from the user-research data.

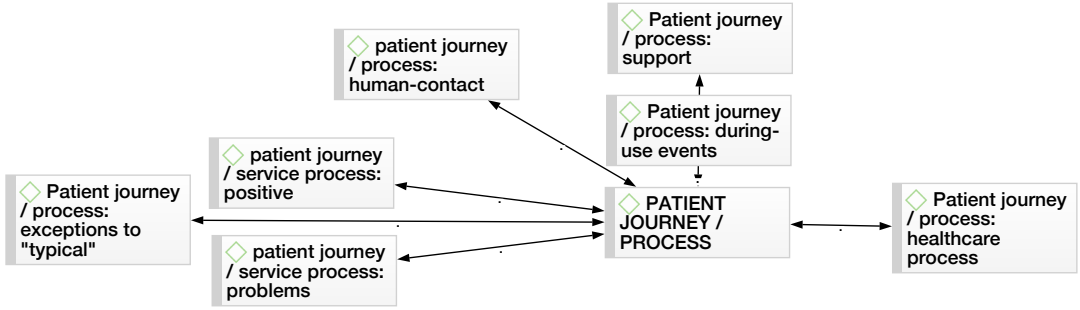


Figure 15: Concepts derived from participants' descriptions of their experiences related to the service process.

As presented in Subsection 5.1.1., in general, the process was experienced positively. As the most positive contact points, participants experienced installing and uninstalling and support. Especially the human-contact in those was valued: installers were considered to be friendly (P2, P3), having expertise (P5), creative in solving problems (P1, P6), and offering personalized solutions (P2, P3). They were trusted (P2, P3). Figure 16 describes the different aspects participants mentioned the contact points of installing and uninstalling. Support was said to work well (P1, P2, P3, P6), and the service was friendly (P3) and humane (P3). P2, P3, and P6 experienced it positively when they were called from NEL when there were some problems with the device. P3 described that he felt cared for because of that.

The severest negative experiences in the service process were related to or caused by the lack of information. For example, P4m/f were poorly informed about the examination. It started from their doctors and hospital and continued in NEL booking call with inconsistent information. It caused them to prepare wrong to the examination and clean the wrong place for the PRU before the installation. They were also given inconsistent information about the duration of the examination period. Other negative experiences were minor, for instance, items that were forgotten to the patient's home in uninstallation (P1, P5). In addition, some participants (P4m/f, P5) felt the wait for the results was long.

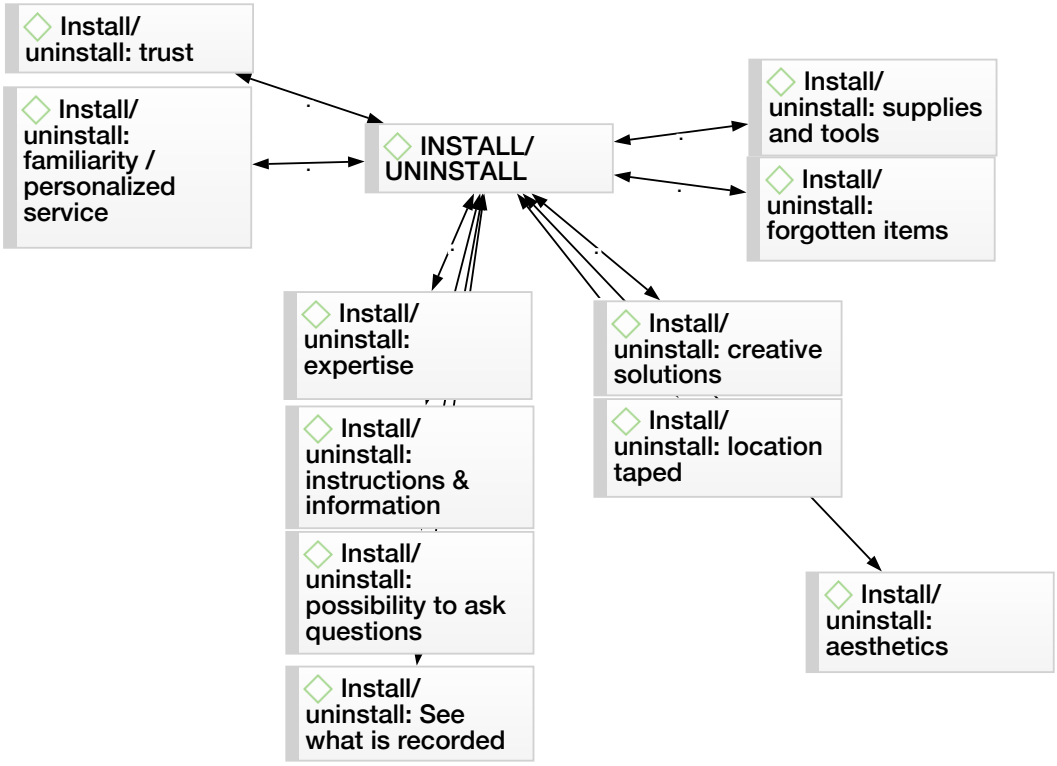


Figure 16: Contact points of installing and uninstall Nelli PRU were experienced mostly positive, with various aspects related to them.

A model of a typical user journey was assembled and summarized from all gathered and analyzed data related to the service process and participants' user journeys (Appendix 3). It is an example journey of the typical process, added with finding that demonstrate potential events from the patient's perspective. It was mainly used for communicating and demonstrating patients' perspectives on the service process of the Nelli examination for NEL stakeholders.

Pointers on the top-level work as topics of the major parts of the journey, in order to help the reader (Figure 17). Their color follows the content related to them below in order to help the reader to see the content related to each part. As an exception to this, indirect content from the point of view of NEL (i.e., events, comments, or other content, which are not at direct control of NEL) is marked on grey background.

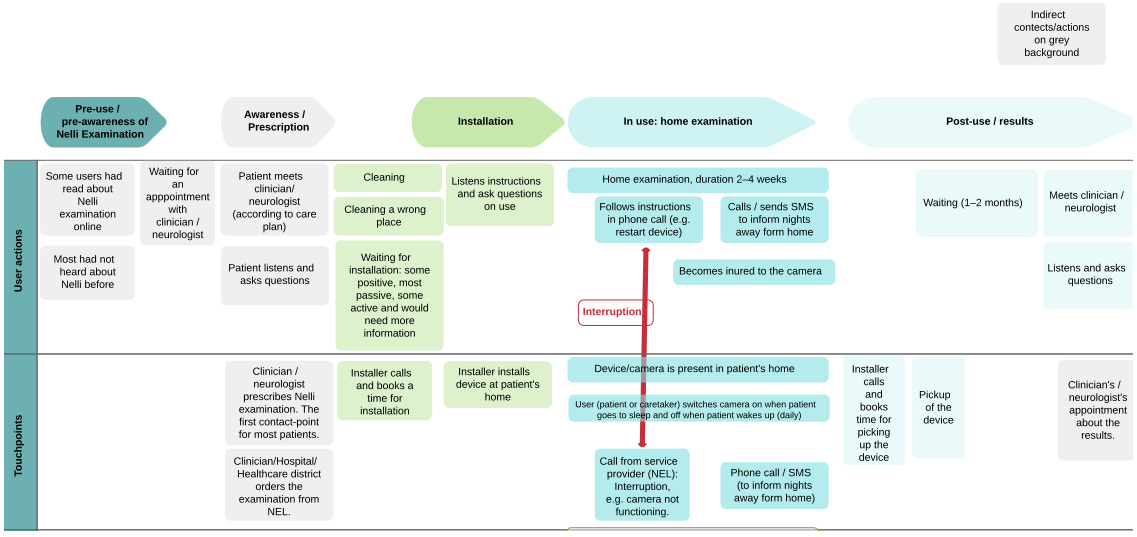


Figure 17: Part of the model of a typical user journey of Nelli examination. The full version can be found in Appendix 3.

In the first horizontal lane (a.k.a. *a swim lane*) from the top, *user actions* in a typical process are described. The next swim lane presents the *touchpoints* between the user and Nelli, including the product, the service, or the service provider and indirect touchpoints through healthcare. The third lane, which is divided with a dotted line, shows examples of *emotions* that arose during the process (Figure 18). The patient journey map includes the major *backstage actions of NEL*. The lane of *Pain points & highlights* lifts up the major themes or findings of each part of the journey. The last lane presents *questions and expectations* of users, especially related to the content-design of the patient tutorial and informing users.

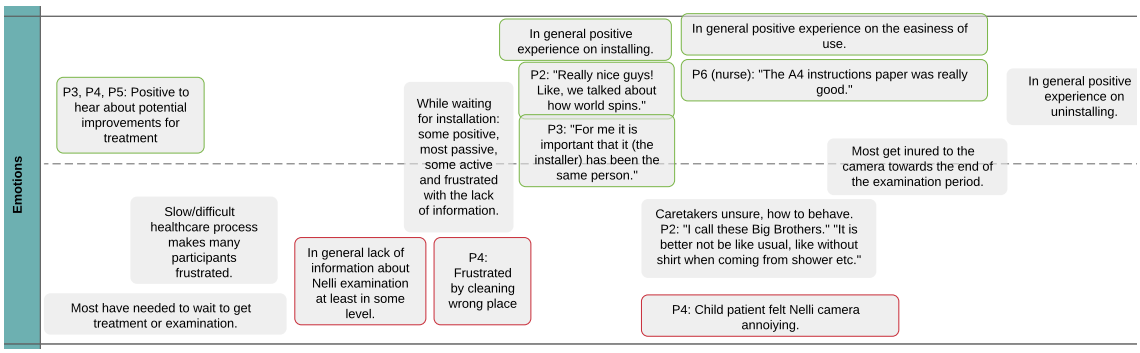


Figure 18: Examples of positive emotions are above the dotted line and negative below.

6. Practical implications of the patient experience research: Content design of a patient-tutorial

The user-research data and findings were used to inform the design of the content of the patient-tutorial website. As stated in Chapter 5, the lack of information was a major theme of negative experiences. Informing patients about the examination was highly dependable on the doctor or the hospital of the patient, and if they did not provide enough information, patients were left uninformed. Those findings, in addition to the needs for information on the examination, as well as for understanding and being informed on the disease, show the demand for the patient tutorial. On the other hand, the current user guide was valued and had good feedback, which should be taken into consideration when designing the new one. In this chapter, I present the relevant findings and explain how they informed the content design, and eventually led to design guidelines and suggestion of contents which were presented for Neuro Even Labs.

6.1. Information needs and users' motivations guide the content design

Although the lack of information was related to different parts of the service process, the emphasis was in the pre-use information (Figure 19). The information it was related to was something that is valuable, starting from the pre-use state. Further, providing a solution for the problem of the lack of information would need to include making the provided information available already before the examination period, preferably as soon as possible after the examination is prescribed, if not even publicly open for the self-initiative and curious potential users. Potential users were mentioned because of a secondary conclusion that most participants had not heard about the Nelli examination before it was prescribed to them; nevertheless, they valued it so high that they wish they had. One participant (P3) even mentioned he had been telling about Nelli to other epileptics he knows because, in his opinion, it was informed or marketed too scarcely.

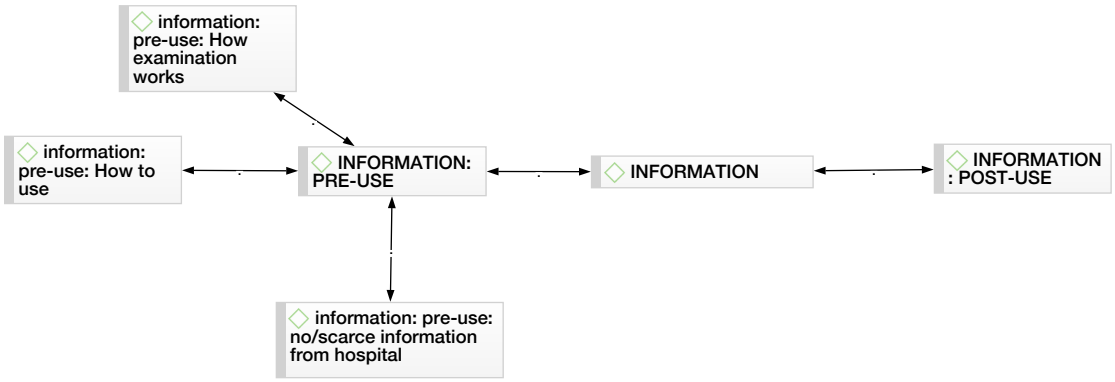


Figure 19: The emphasis of the needed information was in pre-use information.

In this research, we have recognized downsides (mostly related to privacy concerns) of the Nelli examination, which are defeated by the benefits of Nelli, the clinical context and purposes, and personal motivations of users. Therefore, the latter mentioned should be taken into consideration when designing the tutorial.

At a more detailed level, the research informs the content design through the revealed user questions or other points of the lack of information (Figure 20).

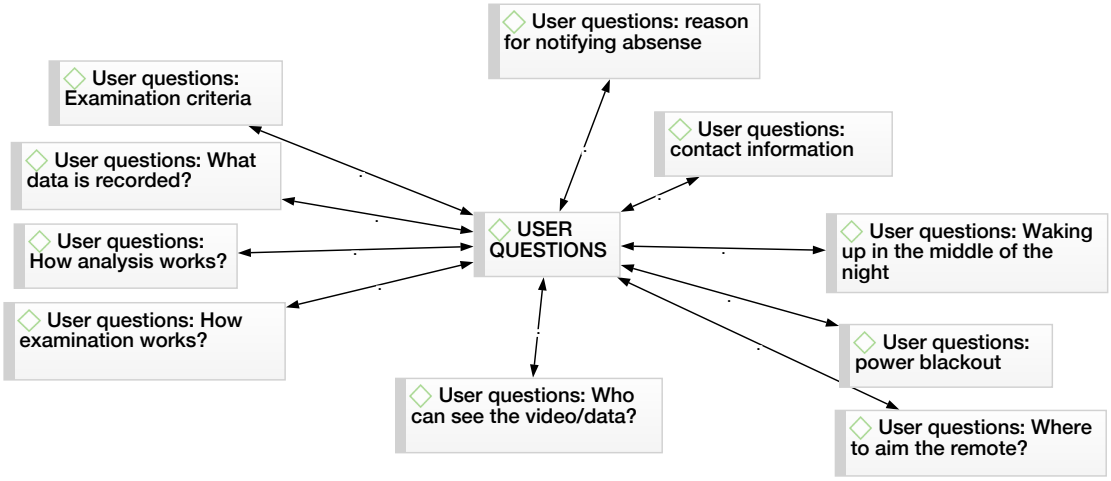


Figure 20: User questions were found in the interviews.

Those are examples of the exact information needs which these participants had. They present the patients', and their caretakers' information needs at a detailed level. However, there are also other factors and stakeholders which are related to the publicity of those issues and the relevance of them in the tutorial. Those factors were left outside the scope of this research and for further consideration of NEL. In addition to these user questions, NEL installers had gathered frequently asked questions before this research. Those combined, a list of questions and answers was gathered and suggested as part of the content.

6.2. Design guidelines of the patient-tutorial content

The findings were summarized as design guidelines of the patient-tutorial content and an example of proposed content for the patient tutorial. The design guidelines of the patient tutorial content are presented here as they were presented to the service provider NEL (language and errors corrected):

1. **Cherish simplicity**: Patients have enough burden; we do not want to increase that. The simplicity and easiness of use of the device and fluency of the service process already support this idea. The patient tutorial should be consistent with that. Participants valued the simplicity of the current user guide paper, and this tutorial should not be made more complex. In order to do so,

I propose short texts about the most important issues. One option to keep the form of the site simple is to use a single page / long scrolling website.

2. **Provide access to more information**: Participants confronted a lack of information in multiple points of their user journey. Although the tutorial should be kept simple, enough information should be available. If and when some information or amount of it contradicts the simplicity, it can be linked from the main page.

3. **Value Privacy:** Privacy concerns and intrusiveness, although being overcome by clinical purposes, are still potential downsides and causes of worry. It is recommended to give an own part for privacy in the patient tutorial, although it was not experienced a big problem among these participants.

4. **Keep the needs and motivations in mind**: The needs and motivations, although not being comprehensively investigated, offer a peek to patients' lives, emotions, and experiences. Benefits are valued. The final need for most is the safety of the patient, and they are interested in everything that they believe takes them towards it.

5. **Answer users' questions**: Participants had a lot of questions. One reason might be insufficient information. Another definitely is that Nelli examination is related to their health and treatment, which is a major factor in their lives, and they are highly interested in whatever is not clear for them related to it. How to answer this call? There are many options for which I suggest some: 1. Possibility to ask questions in a feedback form. 2. FAQ in the tutorial, which needs to keep updated. 3. Installers as a channel of Q/A. (Like they are already and have had good feedback on it!) –> update FAQ from those things they have heard. 4. Active user research.

6.3. Content proposition for the patient tutorial content

The proposed content was presented as a tentative suggestion, which offered the patients' and their caretakers' perspective to the content design of the patient tutorial. However, other stakeholders or other factors were not evaluated in this research. Therefore, it was suggested to be evaluated regarding those matters by NEL. The proposition focused and limited on textual content and concepts of visual elements; however, some suggestions about the division of the content and their presentation included. Further design, especially the graphical design of the website, was not included in this work.

As mentioned in the design guidelines, due to simplicity and usability, the suggested form of the tutorial site was a long scrolling website. The importance of informing and instructing users has been shown in this research. The suggested content is divided into

seven parts, which serve this purpose. In the floating menu, they are shortened and linked, as presented brackets after the headline: 1) *What is the Nelli examination? (Nelli examination)* 2) *Examination and service process (Service process)* 3) *Installation (Installation)* 4) *Examination period (Instructions during use)* 5) *Instructions for patients or caregivers during examination (Analysis)* 5) *Background: How does Nelli examination work? (Service process)* 6) *Privacy (Privacy)* 7) *Frequently asked questions (FAQ)* 8) *Contact information (Contact)*.

The site starts with a general description of the Nelli examination. Due to the tentative nature of this proposition, it may contain errors, for instance, in language. The final version was spell checked before publishing.

> **What is the Nelli examination?**
>
> Nelli examination combines high knowledge from clinical medicine and artificial intelligence (AI) for recognizing epileptic and non-epileptic activities. It helps doctors to get objective information on the frequency and quality of night-time epilepsy seizures. This is crucial for evaluating the need or the effects of treatment.
>
> The benefit of Nelli is that it can be done in the patient's home in normal living circumstances. This allows patients to live their life almost as usual, sleep in their own bed, nevertheless having their seizures registered for weeks.

After that, in the part *Examination and service process*, the patient's process is visualized as a timeline (Figure 21). The visualization is made for demonstrating the idea of presenting content in the form of a timeline. A good and consistent option considering style would be to follow the style that is used on the NEL website.

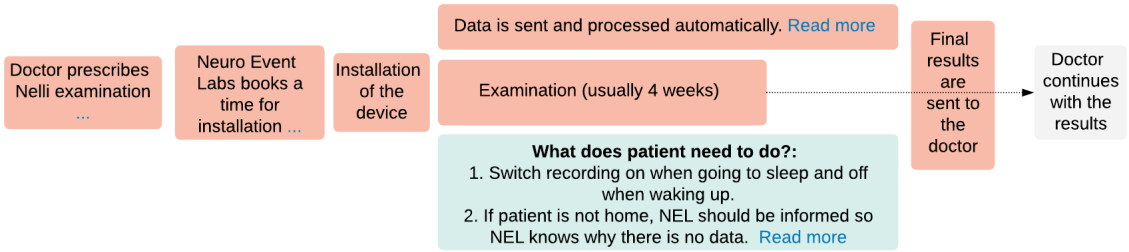


Figure 21: Patient-process timeline

Text boxes in the timeline are expanding. By clicking them, more information can be seen (Figure 22):

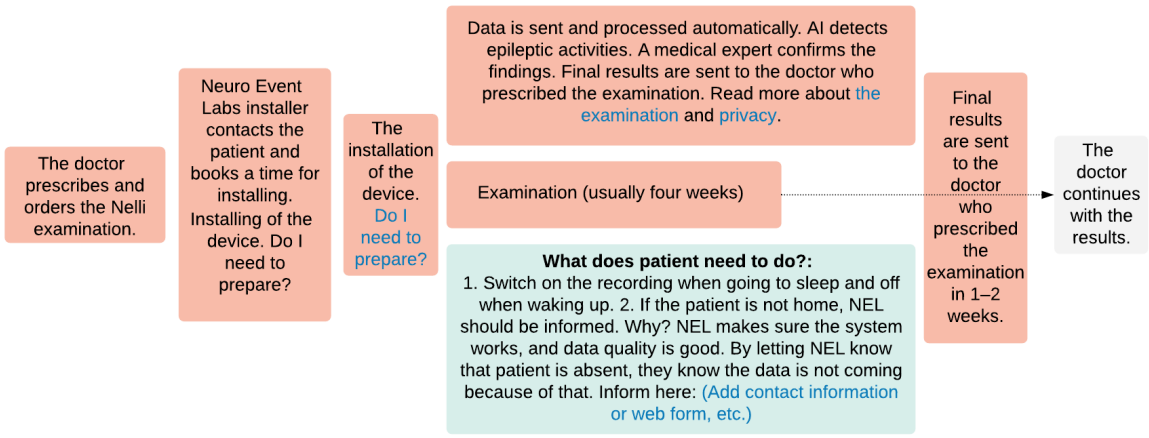


Figure 22: Patient-process timeline expanded

The expanded text boxes contain the following texts:

- The doctor prescribes and orders the Nelli examination.
- Neuro Event Labs installer contacts the patient and books a time for installing.

The installation of the device. Do I need to prepare?

- Data is sent and processed automatically. AI detects epileptic activities. A medical expert confirms the findings. Final results are sent to the doctor who prescribed the examination. Read more about the examination and privacy.
- Examination (usually four weeks)
- What does the patient need to do? 1. Switch on the recording when going to sleep and off when waking up. 2. If the patient is not home, NEL should be informed. Why? NEL makes sure the system works, and data quality is good. By letting NEL know that patient is absent, they know the data is not coming because of that. Inform here: (*Add contact information or web form, etc.*)
- Final results are sent to the doctor who prescribed the examination in 1–2 weeks
- The doctor continues with the results.

The single-page site continues down with other parts, which are also linked and auto-scrolled from the navigation menu and, in certain cases, from the service timeline.

Installation

After doctor has prescribed and ordered Nelli examination, Neuro Event Labs contacts the patient and schedules a time for installation.

Nelli personal recording unit is typically installed by the patient's bed. It requires some space next to patient's bed, however no preparations before the installing is needed. The installer has expertise to find a suitable place for the device. It should not be moved during the examination period.

Examination period

The examination duration, which is decided by the doctor, can vary from 2, 3 or 4 weeks. When the examination period is over installers book a time and uninstalls the device.

The content proposition based on patient-experience research; however, it needed further evaluation considering other stakeholder groups. The suggestion was presented to NEL with remarks of the parts, which need internal evaluation and consideration of other stakeholders.

The previously mentioned parts, general description of Nelli examination, visualized description of the service process, short instructions of parts of the process (e.g., *Installation* and *Examination period*) work towards informing and instructing users about the process. The next part, *Instructions for patients or caregivers during examination* (contend proposition presented below), has the same purpose as the paper version of the user guide, which at the current process is given to users by installers: it focuses on the examination period and the actual use during that.

Instructions for patients or caregivers during examination

1. Switch on/off:

Patient or caregiver switches on the recording when patient goes to bed or otherwise settles in the recording area. When the patient leaves the recording area for a longer time (e.g. gets up from bed in the morning) recording should be stopped.

Start and stop the recording by pressing the red button on the remote control. Point the remote control straight towards the recording device when operating it.

Note: Recording should not be stopped for small breaks like visiting the toilet.

It is important to switch the recording on every night.

2. Inform Neuro Event Labs about being away from home:

If patient is away from home overnight during the examination period, it is recommended to inform Neuro Event Labs about it: call or send an SMS to the Nelli number +358505223080 and mention the days of absence.

3. General instructions

The device should not be moved during the examination period. If it nevertheless for any reason is moved from its location or camera angle is changed, please contact Neuro Event Labs.

Nelli device is operated with a remote control. Start and stop the recording by pressing the red button on the remote control. Point the remote control straight towards the recording device when operating it.

IMPORTANT: DO NOT UNPLUG THE DEVICE FROM THE POWER. TURN THE RECORDING ON AND OFF ONLY FROM THE REMOTE CONTROL.

If there are any questions, the Nelli is behaving strange or the patient will be away some nights, please call or SMS to service number +358505223080.

If needed, you can print a Quick Guide here.

Access to print version is offered because of the good feedback of the user guide paper and the need for a paper version for some of the users.

Next, the proposed tutorial has parts that explain the functionality, working principles, and privacy matters of the Nelli examination. Those parts answer to the needs and questions revealed in this research and are therefore proposed to be briefly included in the tutorial. However, producing the content related to these topics required more expertise on them than I had. Therefore, they were proposed as parts-to-be-filled and questions-to-be-answered. Because of that, these are presented here only partially:

Background: How does the Nelli examination work?

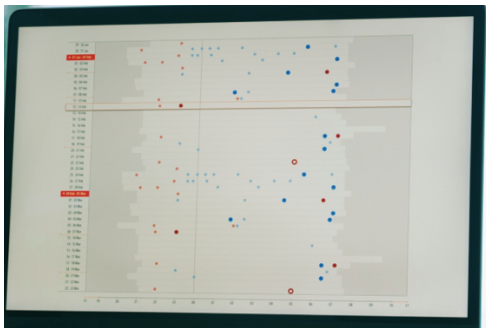
Nelli examination combines high knowledge from clinical medicine and artificial intelligence (AI) for recognizing epileptic and non-epileptic seizures and activities.

Nelli examination uses an algorithm to recognize patterns of epileptic activity from video, audio, and depth-censor data collected by the Nelli personal recording unit. These can be, for instance, patterns of hand or facial movements, voice, or breathing. Nelli personal recording unit sends the secured data to Nelli cloud services to be processed by the algorithm. The system recognizes and highlights seizures. – –

The Nelli algorithm has been validated – –

A summary report, including a graphical report and a possibility to see the highlighted activities from video, is sent to the doctor for further investigation.

(Add picture of this view:)



The part about privacy matters has a brief explanation (approximately 100 words) on how privacy is valued and handled. A link to the *Privacy and Personal Data Protection Policy* is provided for more detailed information.

As a last part of the actual content, *Frequently asked questions* (FAQ) provide a way to offer answers to the questions of the users. This proposed content is combined and edited from the user questions revealed in this research and a previously collected FAQ, which has been part of the installers' guide.

Frequently asked questions

Q: How does it work/what is it all about?

A: The system recognizes seizures based on pattern recognition (e.g., patterns in breathing, voice, or movements) and highlights them for the doctor for further investigation if it is epileptic or not.

Q: What data is recorded?

A: Nelli records video, audio, and depth-censor data.

Q: Why do I need to inform NEL about being away from home overnight?

A: Neuro Event Labs does quality control and makes sure that good quality data is flowing from Nelli personal recording unit. If we know the patient is away from home, we know not to expect data from those nights.

Q: Where is the information stored?

A: All information is stored locally, and after monitoring has ended, it is also sent to the cloud service to be analyzed by the AI. All information is highly secured.

Q: Can somebody hack the system?

A: We take security very seriously. All measures are taken for this not to happen.

Q: Who will see the video?

A: The findings of the video mainly for the doctor to see. Videos may be watched on the part of the seizures by medical professionals who work to help the doctor and patient. Also, there might be a need that professional developing machine learning algorithms need to handle videos and see parts of them then.

Q: Is the video camera on all the time?

A: No. It will record only when the red rectangle is ”breathing.”

Q: Should I turn it on if I feel a seizure coming during the day.

A: Sure, you can if you feel it’s helpful for the doctor. More information on the seizures, the better. But it is not necessary. Night/sleeping time use is enough.

Q: Should I turn it on if I take a nap during the day?

A: Sure, you can if you feel it is helpful for the doctor. More information on the seizures, the better. But it is not necessary. Night/sleep time use is enough.

Q: Does it make a sound?

A: It may make a very low whirl sound, like laptops.

Q: Do I stop the recording if I go to the toilet during the night?

A: No, you do not need to do that. You can leave it on and end the recording only in the morning/after you wake up.

Q: Does it need to be connected to the internet?

A: The system is connected automatically. There is a built-in modem. That is what those antennas are there for.

At the footer of the page are contact information, potentially a link to a web form for notifying absence or feedback, and a link to the general company website of NEL.

7. Discussion and Conclusions

The first section of this chapter discusses the answers to the research questions through six themes found in this research. In the second section the general findings of the research are viewed in the light of previous research. The third section inspects the implications for user experience and patient tutorial of the Nelli examination. Finally, the limitations of this research, and future work are considered.

7.1. Discussion of the research questions

This research found six themes, as an answer to the primary research question, which aimed at understanding, what kind of user experience and other experiences of the patients and their care-takers arise in the use of the Nelli examination at home? Three of them concerned responses resulting from the use of Nelli examination: (1) *Experiences of the use were mainly positive*; (2) *Privacy concerned and influenced the behavior* of the participants; however, *clinical purposes made that accepted*; (3) *Lack of information* was a major theme of negative experiences. Two explained the users' expectations, prepossessions, or other experienced or mental input to the interaction, i.e., their (4) *needs* and (5) *motivations*. One described (6) the *holistic nature of patients' experiences, or patient experience*, which does not limit to the user experience and is influenced by extra-use factors, e.g., patient's history with epilepsy, the treatment of it and the healthcare process.

The primary research question had three sub-questions: (A) what does the user journey of patients, or their caretakers consist of?; (B) What is the role of information in patients' experiences?; (C): how do patients or their caretakers experience the behavioral effects that the examination possibly causes? In addition, the primary research question included research themes and explanatory questions, which were taken into consideration in the data gathering in order to investigate the experiences, as explained in the introduction. The bottom-up approach allowed investigating the experiences openly and follow and investigate further the themes that were emerged during the user research.

Sub-question (A) was answered to the extent which was needed for the practical need of informing the content design of the patient tutorial of Nelli. In addition to that, other findings that could be useful for further research or other product or service development purposes were reported. User journeys of participants were inquired and investigated and further combined and mapped as a model of a typical user journey. Special attention was given to contact points between the user and the service provider, positive experiences, and problems in the service process, and points or periods when users needed to be informed more or better. The quality of these events or situations, including reasons or needs related to them, was investigated.

As a summary of the findings of the user journey, participants experienced the service process of NEL in general positively but had some negative experiences on the healthcare process before and/or after the examination period, especially related to long waiting

times of the examination or the results. However, participants experienced a lack of information related to the service process of NEL. The service itself and the contact points, especially those with human contact, were experienced positively.

Information played an important role in patients' experiences. Information was connected to multiple issues in participants' experiences, and therefore findings related to the sub-question (B) were scattered in the research data, thus required the most work in the data analysis. As a summary, participants had a *need* for information; some of them were motivated by the information, and information contributed to *overcoming downsides* or negative experiences. However, the *lack of information* was a major theme of negative experiences regarding the patient and user experience of Nelli. Participants needed and lacked information about the examination and its process, their own condition, and further the results of the examination. In a more detailed level, the findings related to lacks and needs of information were used to inform the design of the patient-tutorial content. Participants also had a need to provide information about the symptoms for doctors. Information was directly or indirectly related to different motivators of participants, e.g., *personal treatment and health*, *maximizing benefits* (of the examination or treatment), *interest on self-monitoring,* or *benefiting science or medicine*.

Findings of participants' experiences of the behavioral effects caused by the examination (sub-question C) appeared to be more limited than was expected when setting the research question. Excluding some minor exceptions, all found experienced behavioral effects were related to privacy issues. The changes in behavior per se were minor or nonexistent, and participants experienced them tenuous or were not bothered by them; however, multiple participants experienced *pressure* to change their behavior.

7.2. General findings: accepted privacy concerns, lack and need of information, and holistic nature of patient experience

Most findings were in line with the previous research or with some of the unparalleled tracks of the previous research. Although this research alone is not sufficient for drawing conclusions of patient experience at the general level, three themes (2, 3, and 6) offer findings for generalizing the results together with previous or future research.

Findings of *privacy concerns*, their *behavioral impacts,* and *clinical context in making them accepted* (Theme 2) showed that, as found in previous research (Skov et al., 2015; Vines et al., 2013), also participants of this research with severe health conditions with themselves or with their family members, were likely to share their private data. This research also showed the importance of clinical purposes and benefits for patient's health or treatment as major motivators of having the examination despite the downsides. However, this is applied only in the case of patients or their family members. The interviewed nurse felt shame and pressure, or her work being evaluated when she worked in the patient's room where there was a camera. In addition, privacy concerns of participants had

a connection to wrong or missing information about the examination, data handling, or privacy policy.

Corresponding to the theme (3) of *the lack of information* which was found in this research, Andersen et al. (2017) found a theme of experiences of *being uninformed* about examination results, which caused uncertainty and anxiety. Also, the found *need for being informed* was a common finding. (Adams & Blandford, 2005; Andersen et al., 2017; Skov et al., 2015) The importance of *information* or *knowledge* for the patient experience was in line with multiple pieces of research (Adams & Blandford, 2005; Andersen et al., 2017; Grönvall & Verdezoto, 2013). However, participants in the research of Skov et al. (2015) were satisfied in being uninformed of their monitoring results. The difference to Skov's (et al.) results is an important remark considering this theme because their research focused on patients' experiences related to information. The participants in their research were, however, in the risk of sudden death due to their condition. Skov's (et al.) *safety paradox* explained this with avoidance of information related to the illness. In my research, notwithstanding dealing with severe forms of epilepsy, the participants did not report the risk of sudden death. Although this does not mean it did not exist, neither was it investigated, nevertheless they seemed more concerned about the health and life quality and considered some level of information as a mean towards improvements in those, and therefore desirable.

This research revealed more information needs (or lack of information) related to examination than the patient's health condition: for instance, how the examination works (principles, functionality, service process), what outcome it provides, and privacy issues. The reason for this emphasis is that the research focused on the information about the examination. It did, however, show the *need for allowing patients access to more information about the examination* than only the necessities for operating the device. The examination operates in a highly important area of the patient's life, and therefore some users are interested in it at a broader level than only the use and operation. On the other hand, prioritizing information about the core use and the optionality of the extended information is important. Some users are not interested in knowing more at all. Usability and an attempt to minimize the burden caused by the examination are guiding design preferences towards clarity, simplicity, and accessible information on the necessities of use.

Theme 6 described the *holistic nature of patient experience*, which is a parallel finding with multiple studies. (Andersen et al., 2017; Grönvall & Verdezoto, 2013; Opel & Hart-Davidson, 2017; Storni, 2014) Patient experience in the context of the Nelli examination is influenced by extra-use factors. The most relevant of them found in this research were the patient's condition and history with epilepsy, the treatment of it, and the

healthcare process. Considering the perspective of the service provider of the examination, this causes incapability to influence comprehensively to all of the patients' experiences. On the other hand, this research showed signs of recovering previous negative experiences of healthcare due to positive experiences caused by the examination and the process related to it.

Finally, although the needs and motivations of users found in this study are individual and tied to their context of epilepsy and Nelli examination and therefore not generalizable, it can be worthwhile to mention the found relevance of those to the experiences of users. Understanding users' needs and motivations in UX and human-centered design can be utilized to help and guide users in overcoming the necessary downsides of different examinations or treatments.

7.3. Implications for user experience and patient tutorial of Nelli examination

Considering the user experience of Nelli in particular, results show few downsides and areas of improvement for mostly positively experienced technology and service (themes 1, 2, 3) and describe patients' and their caretakers' experiences and perspective in the form of *needs* (4), *motivations* (5) and other extra-use experiences (6). Particularly the theme of the *lack of information* (3) is a relevant finding regarding the pre-set goal to inform the content-design of a patient tutorial. Compendiously, the participants felt uninformed about how the examination, including the technology and the service, works, what kind of results it provides, can they see those results, and who overall can see the data it records. The positioning of these areas of the lack of information was evaluated in the light of the found knowledge about user journeys. In addition, the following findings provided information for content design: the privacy concerns of participants (Theme 2), their needs for information about the examination and their medical condition, and the findings related to their motivations regarding the examination.

From this information, *design guidelines* were summarized: *Simplicity*; *Access to more information*; Users are *concerned about privacy* and providing information about it is recommended; The *needs and motivations of users* are recommended to keep in mind in the design work; Users have numerous *questions about Nelli and its context* because it operates in a highly important area of their lives, and those questions are recommended to be answered or noticed. These guidelines take into consideration the three dimensions for user experience (UX) research and design in patient-centered e-health by Andersen et al. (2017), *connectedness*, *comprehension*, and *compassion*, which were presented in Chapter 3.

7.4. Limitations and future work

This research had some limitations. The sample size of this research was small. When the participants were recruited, half of the candidates refused, some because they were busy,

some because of their health condition. As stated before, patient experience and user experience of the patient are influenced by, for instance, the patient's health condition. Therefore, particularly the absence of participants with a particularly difficult current health condition can be likely to create false-positive results. It is also possible that the ones who accepted the research invitation are more open towards scientific research and the applications of it and novel things in general. In fact, this was seen in the interview data in the case of two participants (P1, P3), as reported in Subsection 5.1.5. This can also impact on their experiences about Nelli and create circumstances for false-positive results.

The user-research and data-analysis were done solely by one person. This limits the reliability of the analysis. It is also possible that the selection of previous literature has influenced the data analysis; however, not likely the data gathering. Most of the literature was brought to the process, not until the phase of the data analysis.

Contrary to Andersen et al. (2017), this research did not show signs of participants' emotions being grounded on negative feelings. This research alone cannot reliably show if there is a difference and what would be the reasons for it. It is an interesting question for future research, how different medical conditions influence the feelings related to their technology-assisted self-monitoring.

Considering the content design of the patient tutorial of Nelli, it was planned to test and evaluate the design proposition with participants who had not used Nelli before. This plan was canceled due to the COVID-19 situation during the time the research was done. Therefore, it is recommendable that the design would be evaluated before or after publishing the content.

It was said in the introduction that the impact of HCI-research in clinical practice has been low. Based on the results of this study, the user experience of Nelli was, in most parts, on a good level. The reasons behind the successful UX was not investigated. It can be due to the general expansion of UX knowledge to healthcare or, for instance, due to the nature of NEL as an external service provider compared to projects of public administration or any arbitrary reason. However, it is a matter of future research, has the user experience of medical self-examination technologies improved in general and what factors or reasons that improve user experience can be considered in user experience design.

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Appendices

Appendix 1: Written consent for user research

Käyttäjätutkimuksen tiedonhankinnan tallennuslupa

Sinua on pyydetty osallistumaan Nellin potilas- ja käyttäjäkokemustutkimukseen, joka on osa Jouko Makkosen pro gradu -työtä (Tampereen yliopisto, Human-Technology Interaction -maisteriohjelma) ja Neuro Event Labs Oy:n tutkimus- ja kehitystyötä. Tutkimuksen tavoitteena on ymmärtää paremmin potilaita tai muita käyttäjiä, ja sen ymmärryksen perusteella kehittää käyttäjäystävällisempää palvelua ja tuotteita ja lisätä tietoa vuorovaikutteisen teknologian alalta. Tutkimuksen tuloksia hyödynnetään Neuro Event Labs Oy:n tuotteiden ja palveluiden kehittämisessä sekä Jouko Makkosen pro gradu -tutkielmassa.

Tutkimuksen teemat käsittelevät esimerkiksi yleisesti käyttäjän kokemusta tuotteesta, käyttäjän ”matkaa” tuotteen käyttäjäksi ja eri kontaktipisteitä tuotteeseen ja palveluun, yön aikana kuvatuksi tulemista ja laitteen käyttöä omassa kodissa.

Tutkimus on monimuotoinen. Siihen voi sisältyä haastatteluja joko puhelimitse tai kasvotusten ja mahdollisesti jatkohaastatteluja, kyselyitä ja havainnointia. Ensihaastattelun jälkeen toivotaan jatkoa vähintään toisen haastattelun verran. Käytettävistä tutkimustavoista, aikataulusta ja tutkimuksen jatkosta sovitaan osallistujan kanssa erikseen.

Haastattelut tai muut tiedonhankintatilanteet voidaan nauhoittaa, tutkija voi tehdä muistiinpanoja ja sovitusti ottaa valokuvia. Nauhoittamisesta, kuvaamisesta ja muusta digitaalisesta tallentamisesta ilmoitetaan ja kysytään lupa suullisesti tilanteessa erikseen.

Tutkimustuloksia käsitellään nimettöminä ja tieteellisen tutkimuksen etiikkaa noudattaen. Testin tulokset raportoidaan tavalla, josta yksittäistä osallistujaa ei voi tunnistaa. Tutkimuksen tulokset toimitetaan Nellin kehittäjille, jotta he voivat edelleen kehittää tuotetta ja palvelua.

Voit halutessasi lopettaa testitilanteen missä tahansa vaiheessa.
Vastaan mielelläni kysymyksiin, jos Sinulla on jotain kysyttävää.

Allekirjoittamalla tämän lomakkeen, suostut yllä oleviin ehtoihin.

Päivämäärä ja paikka: _____

Allekirjoitus: _____

Nimen selvennys: _____

Tutkimuksen toteuttaa:

Nimi: Jouko Makkonen, jouko.makkonen@tuni.fi, 0445274506

Appendix 2: Nelli – Home recording user guide

neuroeventlabs

NELLI – HOME RECORDING USER GUIDE

IMPORTANT: DO NOT UNPLUG THE DEVICE FROM THE POWER. TURN THE RECORDING ON AND OFF ONLY FROM THE REMOTE CONTROL.

How to start and stop the recording

1. Start the recording when the patient goes to bed or settles in the recording area.
2. Stop the recording when the patient leaves the recording area for a longer time. Recording should not be stopped for small breaks like visiting the toilet.

User Instructions

Start and stop the recording by pressing the red button on the remote control. Point the remote control straight towards the recording device when operating it.

The device is on standby mode when the blue power light is on. The device is recording when the red color ring is blinking softly.

Neuro Event Labs Oy contact information

If you have any doubts about the usage of the device, uncertainty about the success of the recording or you have anything to ask, don't hesitate to contact us at:

Service: p. 050 52 23080

Appendix 3: Patient journey map/model of typical user journey of Nelli